Investigating the outcome of the initial assessment at national transgender health service: Time to review the process?

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Investigating the outcome of the initial assessment at a national transgender health service: Is it time to review the process?

Abstract

Background: Globally there is a lack of a standardised assessment process prior to the initiation of gender affirming medical interventions and consequently there is a discrepancy in this process among different transgender health services.

Aim: The main objective of this study is to investigate the outcome of the initial assessment process at a national transgender health service.

Method: The outcome of people over the age of 17 years, assessed at a large national transgender health service in the United Kingdom during a two year period was categorised into: 1) recommendation for cross-sex hormone treatment, or: 2) no recommendation for cross-sex hormone treatment. In addition, 200 case notes were reviewed in order to investigate the level of agreement between the two clinicians involved in the assessment process.

Results: During the study period a total of 617 people completed their assessment at the service. Following assessment 380 (61.6%) patients were recommended for cross-sex hormone treatment, leaving 237 (38.4%) patients who required a longer assessment period or were discharged. The factors associated with being recommended for cross-sex hormone treatment were: having socially transitioned, not smoking, having initiated cross-sex hormones prior to assessment, being older, and assigned male at birth. Out of the 200 case notes reviewed, agreement between assessor 1 and 2 (3 months apart) was found in 88 % (n= 176) of the cases.

Discussion: Although the results of the study may not be generalizable to other international centres, questioning the assessment process and the role of the assessors is important to ensure treatment is offered in a timely and efficient manner. The findings from this study suggest that the routine inclusion of two assessors needs to be reviewed.

Keywords: Assessment, Transgender, Outcome, hormones, Transgender health services
Investigating the outcome of the initial assessment at a national transgender health service:  

Is it time to review the process?

Introduction

In the context of the high demand for transgender health services (de Vries, Krekels, T'Sjoen, Algars, & Mattila, 2015) and the predicted increase in demand (Arcelus et al., 2015; House of Commons, 2016), timely access to gender affirming medical treatment (whether cross-sex hormones and/or surgeries) presents a major healthcare challenge (Joseph, Cliffe, Hillyard, & Majeed, 2017; Reisner et al., 2016). Given the positive effects of gender affirmative interventions on the wellbeing of treatment seeking transgender people (Bouman et al., 2016a,b; Dhejne, Van Vlerken, Heylens, & Arcelus, 2016; Millet, Longworth, & Arcelus, 2016), there is a need for innovative strategies to improve access to gender affirming treatments (Reisner et al., 2016).

Health services for transgender people are guided by the World Professional Association for Transgender Health Standards of Care, 7th edition (SOC-7; Coleman et al., 2012). The SOC-7 describes the need to gather the following information as part of the assessment process: assessment of gender identity and gender dysphoria, history and development of gender dysphoric feelings, the impact of stigma attached to gender diversity on mental health, and the availability of support from family, friends, and peers (Coleman et al., 2012). Possibly due to the lack of empirical evidence regarding the assessment process, the SOC-7 does not provide guidance on the number of appointments the assessment process should comprise and/or the number of clinicians that should be involved in the assessment process. As a consequence, there is not a standardised procedure that outlines the process of assessing a person who has been referred to a transgender health service. There is, therefore, great variation in assessment processes followed among services worldwide.

As in many European countries, in the United Kingdom (UK) health services, including those for transgender people, are state funded. Currently there are seven transgender health services for people 17 years and older in the UK. Recently, these seven services have experienced a significant
increase in demand over time. For example, the Nottingham Centre of Transgender Health, a
nationally commissioned centre that offers care and treatment to people living in England and
Wales, received 1030 new referrals in 2016, 850 new referrals in 2015, 540 new referrals in 2014,
and 360 referrals in 2013. This increase in demand is not unique to this centre as a similar pattern
has been describes by other national and international services (de Vries et al., 2015; House of
Commons, 2016). As a consequence of the increase in referral rates, extremely long waiting times to
access state funded transgender health services in the UK have been experienced by many trans
people seeking treatment.

Currently the assessment process offered at most transgender health services in England and Wales
takes place over at least two appointments and involves two independent professionals. As part of
the assessment process, mental health needs are considered, but these would not usually prevent a
recommendation for gender affirming medical treatment (SOC-7; Coleman et al., 2012). Gender
identity is also assessed – this being a psychological identification of oneself or the internal sense of
being in relation to one’s gender. How people feel about their gender is, of course, very personal
(Bouman & Arcelus, 2017) and only the individual truly knows how they feel about their gender and
how they identify (Coleman et al., 2012). In view of this, assessing an individual’s gender identity
may be unnecessary as they are in the best position to identify their gender. On the other hand, it is
important that the stability of gender identity and expression is ascertained due to the irreversibility
of gender affirming medical treatment. Hence, the National Health Service (NHS), which funds all
healthcare, argues that there is benefit from a decision-making process within transgender
healthcare services regarding these interventions that involves more than one clinician and, despite
there being a lack of direct evidence to support this, it is considered as best practice in some
countries.
Due to the lack of studies investigating the outcome of assessments at transgender health services, there is no broad consensus between clinicians as to what the most appropriate, effective and efficient process should be. Ideally, clinical practice should be informed by empirical evidence and therefore more research is warranted in exploring the best practice regarding assessment at transgender health services. This research should begin by investigating what the outcome of the current assessment process is. Such knowledge will inform initiatives to standardise the assessment process at transgender health services and develop the most efficient service for trans people. Consequently, the main objective of this study is to investigate the outcome of the assessment process at a large national transgender health service in the UK, which is likely to be representative of the rest of the UK. The study has several specific aims: First, to describe the different recommendations made by clinicians following assessment. Second, to compare patients who had, and patients who had not, been recommended for initiation of cross-sex hormone treatment on pre-assessment variables. Lastly, to investigate the levels of agreement between the two clinicians involved in the assessment process in order to investigate whether a second clinician aids in the assessment outcome.

Method

Recruitment and participants

The study took place at the Nottingham Centre for Transgender Health within the National Health Service (NHS) in the United Kingdom. This is one of the larger transgender health clinics in Europe and receives more than 1000 referrals a year from people living in England and Wales. As per other UK services, referrals to the service are received mainly from primary care physicians. People cannot self-refer to this service. The routine assessment process consists of two separate appointments with two independent senior clinicians of 60 to 90 minutes each and a third appointment involving both clinicians, plus the individual being assessed. A significant other can be invited by the patient into the third appointment. There is usually a gap of 3 months between each assessment
appointment. Due to capacity issues, following referral to the centre, patients can expect to wait approximately 18 months for the assessment process to begin, which is clearly unacceptable. The service accepts referrals of people aged 17 and over with a number of referrals being transferred from the NHS Gender Identity Development Service (the child and adolescent service) in London (UK) or its satellite service in Leeds (UK). Following the assessment, a decision is made as to whether the individual is ready and suitable to enter into the treatment programme (e.g., prescription of cross-sex hormone treatment). In order for transgender people to be accepted into the programme, it is usual for people to amend most of their legal documentation, including changing their name, which is a straightforward process in the UK. Aside from the assessment considerations detailed above, if there are no physical contraindications, patients will be prescribed cross-sex hormone treatment, if they so wish. A co-existing mental health diagnosis, or a diagnosis of autism spectrum disorder is no contra-indication to enrol into the treatment programme (Glidden et al., 2016). Following a minimum of 6 months of living in their gender role, transgender males can then be considered for chest reconstructive surgery. Usually transgender males and females wishing to undergo genital surgery will be referred for this once they have lived in their gender role for a minimum of one year.

Procedure

People referred to the Centre are invited to complete a socio-demographic questionnaire before the assessment is due. Information regarding transitional status as well as information regarding whether the person is smoking is also collected. Furthermore, information is collected with validated questionnaires regarding mental health, body image and quality of life issues.

For the first aim of the study, the clinical notes of all patients assessed at the centre during a two-year period (2014-2016) were examined. The outcome of the assessment was coded into two groups: 1) immediate recommendation to enter into treatment programme (or direct access to
treatment- DAT), or; 2) not recommended to enter into treatment programme (no direct access to
treatment- NDAT). For the second aim, socio-demographic characteristics, including age and
assigned sex as well as transitional status pre-assessment (coming out to others, name change,
social gender role transition) were collected and both groups (DTA and NDTA) were compared on
these variables. For the last aim, a sample of randomly selected active case notes was examined by
two of the researchers (A S-A and JA) (n=200). The recommendations made by the first and second
assessor in each case were coded into the same two categories used in the first aim (DAT and NDAT).
Where disagreement between assessors in the outcome recommended was identified, factors
(socio-demographics) associated with disagreement were explored. These factors included age at
the time of referral, ethnic origin, assigned sex, and gender identity.

The study was a part of a longitudinal study, which received ethical approval from the NHS Research
Ethics Committee and from the Research and Development Department from the Nottinghamshire
Healthcare NHS Foundation Trust in accordance with the Health Research Authority (HRA, 2013).

Data analysis

All quantitative data analyses were performed using SPSS 22 (IBM, 2013). For the aims one and
three descriptive statistics were examined. For aim two comparative analyses were undertaken.
Data were positively skewed in both groups (DAT and NDAT) and non-normally distributed, as
demonstrated by significant ($p=0.002$) Kolmogorov-Smirnov tests. Therefore, non-parametric tests
were selected. For this second aim where comparison between groups are described, Mann-
Whitney U tests and Chi-square tests were conducted. The level of significance used was $p < 0.05$.

Results

Aim 1: outcome of the assessment process
During the study period, a total of 617 people completed their assessment at the service. Following assessment 380 (61.6%) were recommended direct access to cross-sex hormone treatment (DAT). A total of 237 (38.4%) people were not recommended direct access to cross-sex hormone treatment (NDAT). In the majority of the cases where treatment was not initiated (or not immediately initiated) the reasons were related to requiring a longer assessment process (n= 97, 40.9% of NDAT), not providing evidence of a social gender role transition, including change of name (n=52; 53.6% of the group requiring longer assessment). In 11 (4.6%) cases, psychotherapy was recommended, while 12 (5.1%) people did not attend the second appointment and therefore were discharged from the service. In nearly 40% of the cases (n=93; 39.2%) medical transition was not felt to be appropriate due to personal factors (such as non-acceptance from partners and complexities surrounding this) explored during the assessment process, in those cases after a series of appointments the patient and the clinician agreed to discharge the patient from the service. Following assessment, 24 (10.1%) of the NDAT group were unclear about their gender and felt that they did not want to transition.

Aim 2: comparing DAT to NDAT on pre-assessment socio-demographic variables

The mean age for the whole group was 30.65 years (SD=14.03) with a minimum of 17 years and a maximum of 79. People not offered direct access to treatment appeared older (mean=31.65; SD=14.20) than people in the DAT group (mean=30.02; SD=13.90), but the difference between groups regarding age was not significant (U=40944.00; z=-1.90; p=.057). A Chi-square test indicated a significant association between assigned gender and direct access to treatment with more people assigned male at birth than assigned female at birth being offered direct access to the treatment programme (DAT; see Table 1). In the NDAT group there were significantly more people who were described as a smoker; who had not come out as transgender; and who had not made a social gender role transition in comparison to the DAT group pre-assessment (see Table 1). Additionally, people who had taken hormones pre-assessment (obtained via the Internet or via private medical practitioners) were significantly more likely to be recommended for the initiation of gender
affirming medical interventions after the assessment process than people who had not taken cross sex hormones pre-assessment (see Table 1).

Aim 3: levels of agreement between the outcome of first and second assessor for entry into the treatment programme

Out of the 200 case notes reviewed, agreement between assessor 1 and 2 (3 months apart) was found in 88% (n= 176) of the cases. In most cases (n=23; 95.8%) disagreement between assessor 1 and 2 was present because during the first assessment appointment the patient had not made a social gender role transition (and therefore the clinician did not recommend the initiation of gender affirmative medical treatments), but by the time of the second appointment with assessor two, a social gender role transition had been made. There was only one case where the first assessor recommended treatment, but not the second assessor. Of the patients with discordant assessment recommendations, the majority (n=19; 82.6 %) were people assigned male at birth. In both instances where a difference in treatment recommendation was found for people assigned female at birth, this was related to them obtaining documents in the interim. No significant differences were identified for the other socio-demographic data collected.

Discussion
This study aimed to investigate the outcome of the assessment process at a large national transgender health service in the UK and explore factors associated with people who were and were not recommended for cross-sex hormone treatment. It was hoped that obtaining this information would inform the development of initiatives to improve the assessment process in order to make it more efficient. The findings from this study demonstrated that more than 60% of the people assessed at this large national centre in the UK were recommended for gender affirming medical
treatment following routine assessment. The reasons for why treatment was not recommended were associated with the person not having changed their legal documents, including name. Socially transitioning before physical gender affirming medical interventions is not mandatory in some transgender health services and not a requirement stipulated by the SOC-7 (Coleman et al., 2012). However, some clinicians may feel the need for people to make a social gender role transition before considering cross-sex hormones in order to determine how this will be orchestrated and be accepted by the person themselves and others around them. This requirement once again lacks evidence and future studies should investigate the role that socially transitioning prior to cross-sex hormones has on outcomes.

The current study also demonstrated that in the vast majority of the cases both assessors involved in the assessment process agreed regarding recommendation for gender affirming medical treatment. Due to the high level of agreement, the need for two different assessors in the assessment process should be questioned. Having one assessor would decrease waiting times at transgender health services. Once again the involvement of two different assessors for interventions other than gender affirming genital surgery is not a requirement stipulated by SOC-7 (Coleman et al., 2012). Levels of expertise and seniority at the Nottingham Centre for Transgender Health are high, which may result in higher levels of agreement between assessors; and therefore, transgender health services with more junior staff may have different findings. In these circumstances, having two assessors may be appropriate, although further research is required.

To facilitate the assessment process at transgender health services, being able to differentiate between people who are ready for gender affirming medical treatment from those who are not, is important. So far, this study is able to demonstrate that trans people who have socially transitioned, do not smoke, are on cross-sex hormones (pre-assessment), are older, and are assigned male at birth are more likely to be recommended for gender affirming medical treatment following the
assessment process than people who have not socially transitioned, smoke, have not taken cross-sex hormones, are younger, and are assigned female at birth. Some of these findings will be associated with the requirement by this service to socially transitioning before gender affirming medical treatment can be considered. Services where social transitioning pre-treatment is not a requirement may have an even higher number of people entering the treatment programme for initiation of cross-sex hormones. Future factors such as the role of social support (Bouman et al., 2016c; Davey, Bouman, Arclus, & Meyer, 2014); age (Arclus, Claes, Witcomb, Marshall, & Bouman, 2016); and certain characteristics such as features of autistic spectrum found to be high among this population (Glidden, Bouman, Jones, & Arclus, 2016) could also be considered in future studies. Future studies may also investigate the role of assessment in reaching diagnostic criteria in view of the future ICD-11 diagnosis (Beek et al., 2016, 2017).

The majority of the disagreement between assessors in reaching a recommendation for gender affirming medical treatment was found to be influenced by temporal factors, as opposed to the fact that assessments were undertaken separately by two senior clinicians. It may well be that the first assessment acted as a ‘spur’ to act (i.e., make a social gender role transition). Further, long-term outcomes from gender affirming medical treatment have not been well studied and have mainly focussed on mental health (Dhejne et al., 2016; Heylens et al., 2014). Rates of ‘regrets’ with transition indicated by a wish to de-transition back to assigned gender at birth are rare (Bouman et al., 2014) and there is no evidence that a prolonged assessment process at a transgender health service improves outcome (regarding mental health) or reduces the rate of regret. Although the results of the study may not be generalizable to other international centres, especially those which are not taxpayer funded, questioning the assessment process and the role of the assessors in the field of transgender health is vital and timely. This will allow the development of a more efficient way of assessing trans people’s readiness for cross-sex hormone treatment and reduce obstruction that many trans people face accessing transgender healthcare. A more efficient and effective
Assessment outcomes at a transgender health service

The assessment process will reduce waiting lists, which will not only reduce costs of state funded health services, but will primarily reduce the suffering of many people waiting to commence gender confirming medical treatment.

Declaration of Conflict of Interest

The authors have no conflict of interest to declare.

References


URL: http://mc.manuscriptcentral.com/wijt Email: walterbouman@doctors.org.uk
Table 1: Chi-square tests comparing pre-assessment socio-demographic variables for people who were (n=380) and were not (n=237) recommended for the treatment programme after the initial assessment process

<table>
<thead>
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<th>DAT patients (n=380)</th>
<th>NDAT patients (n=237)</th>
<th>$\chi^2$</th>
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<tr>
<td><strong>Sample size (%)</strong></td>
<td></td>
<td></td>
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<tr>
<td>Mean ($SD$) age</td>
<td>30.02 (13.90)</td>
<td>31.65 (14.20)</td>
</tr>
<tr>
<td>Assigned female</td>
<td>167 (74.22%)</td>
<td>58 (25.77%)</td>
</tr>
<tr>
<td>Assigned male</td>
<td>213 (54.33%)</td>
<td>179 (45.66%)</td>
</tr>
<tr>
<td>Smoker</td>
<td>44 (49.43%)</td>
<td>45 (50.56%)</td>
</tr>
<tr>
<td>Non-smoker</td>
<td>336 (63.63%)</td>
<td>192 (36.36%)</td>
</tr>
<tr>
<td>Hormones</td>
<td>130 (81.25%)</td>
<td>30 (18.75%)</td>
</tr>
<tr>
<td>No hormones</td>
<td>245 (54.68%)</td>
<td>203 (45.31%)</td>
</tr>
<tr>
<td>Come out as transgender</td>
<td>324 (66.52%)</td>
<td>163 (33.47%)</td>
</tr>
<tr>
<td>Not come out as transgender</td>
<td>56 (43.07%)</td>
<td>74 (56.92%)</td>
</tr>
<tr>
<td>Social gender role transition</td>
<td>218 (77.30%)</td>
<td>64 (22.69%)</td>
</tr>
<tr>
<td>Not made a social gender role transition</td>
<td>162 (48.35%)</td>
<td>173 (51.64%)</td>
</tr>
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</table>

*p<0.05, **p<0.01, ***p<0.001; DAT=Direct access to hormone treatment, NDAT= No direct access to hormone treatment