Gender dysphoria: prevalence, pathways and experiences of people with autism traits

SHORT REPORT

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Evidence Brief

Why did we start?

While increasing numbers of people with autism traits appear to be in contact with specialist gender services in Northern Ireland (NI), sound evidence on the prevalence, pathways to service and mental health of such patients is limited. Additionally, we know little about the experiences of people with gender dysphoria and how they navigate support and care.

What did we do?

The GIFTS study (Gender Identity - Finding and Transforming Services) is the first in NI to examine the needs of individuals living with gender related distress and autism traits. It examined the autism trait prevalence, mental health needs, care pathways and lived experiences of treatment seeking adolescents and adults. GIFTS is a mixed methods study, using a cross-sectional survey, in-depth interviews and case note review. We compared people with autism traits to those without autism traits on a range of mental health measures and interviewed them about their lived experience of gender related distress and how they experience services. The study focused on autism traits rather than autism diagnosis as an autism diagnostic assessment requires a multidisciplinary team, which would have been outside the remit of this study. It is also important to note that the presence of autism traits does not translate into an autism diagnosis for everyone.

While primarily focused on treatment seeking people GIFTS also incorporates a small community sample not involved with specialist gender services.

What answer did we get?

Using a conservative assessment we found an autism trait prevalence of 17.2% in participants (N=124). Over 50% of all participants presented with high risk of suicidality, anxiety and previous experiences of multiple childhood traumatic events. People with autism traits were more likely than other participants to experience anxiety, depression and childhood trauma.

Individuals with autism traits requested treatments, similar to other participants. From the in-depth interviews (N=40), we examined the importance of *impression management* and *camouflaging* strategies used by participants when presenting to services. Importantly, there was considerable mistrust towards services and many participants believed that ‘successful’ outcomes were dependent on making an *authentic presentation* to clinicians, a self-perceived performance experienced as more challenging for non-binary individuals. Lengthy waiting lists increased the distress of participants.

What should be done now?

Future planning for service delivery should incorporate strategies and environment changes that facilitate engagement for those with social communication difficulties. The needs of non-binary individuals must be considered carefully in view of their marginalization in clinical services and in the wider society.

Background

As a clinical nurse specialist working in the regional young person gender identity development service, I noticed a large increase in referrals of young people over the last five years. This trend was also seen in the adult gender service population. It was notable that a striking proportion of the referrals to both specialist gender identity services appeared to have autism or autism traits, something not unique to NI, and also observed in specialist centres in Europe and North America. The reasons for this were unclear. Co-existing autism traits created additional challenges for clinicians during assessment for gender affirming interventions - frequently related to individuals engaging in reciprocal verbal conversations with staff, which many found difficult.

There was a clear need to increase our understanding of the needs of individuals presenting with additional social communication difficulties and to develop responsive, person-centred services. This complex area required research to improve clinical pathways, skills and knowledge for clinicians and flexible treatment options for those with additional autism traits. It was clear however, that there was a need to understand the social and psychological factors associated with this phenomenon, the referral pathways, decision-making processes and mental health outcomes for individuals with gender dysphoria. With relatively little autism research activity in NI and, to my knowledge no research that previously explored autism traits and gender dysphoria, there was a clear gap in research knowledge.

Aims and Objectives

(1) To describe the sociodemographic and other characteristics of people either currently attending specialist gender services in Northern Ireland between August 2017 and July 2019 or who had previously attended services.
(2) To ascertain the prevalence of autism traits among patients in specialist gender services.
(3) To examine the prevalence of mental health difficulties (anxiety, depression, suicidality, borderline personality traits, experience of childhood and recent trauma) in people attending specialist gender services in NI.
(4) To examine possible differences in service pathways, experiences and outcomes between people with autism traits and people without autism traits.
(5) To examine the experiences of individuals attending or not attending specialist gender services (presentation of individuals to services/ experience of services/ awareness of gender incongruence)

Methods

GIFTS is a mixed-methods study, combining both quantitative data from a cross-sectional survey of individuals (N=124) attending gender identity services in Northern Ireland and qualitative data derived from individual interviews (N=40).
It is recognised in the literature that autism screening tools rather than diagnostic tools may lead to false positives. In order to reduce the likelihood of false positives the GIFTS study used a combination of autism screening tools (Autism Quotient-AQ, Baron-Cohen et al., 2001; Cambridge Behaviour Scale (Empathy Quotient- EQ), Baron- Cohen and Wheelwright, 2004; RAADS- 14, Eriksson et al., 2013) and chart review for clinical diagnosis of autism if applicable.
In combination, the measures and chart review provided a robust indication of the presence of autism traits. This required participants to score 32 or above on the AQ, RAADS-14 and below 32 on the EQ measure. The cut-off points for each measure were based on suggested cut-off points in the literature. Individuals in the GIFTS study with high scores on the screening measures were supported to access full diagnostic assessments if they wished to do so.
Within the GIFTS study, a demography questionnaire and a number mental health measures (Hospital Anxiety & Depression Scale (HADS), Zigmond and Snaith, 1983; Suicide Behaviour Questionnaire Revised (SBQR), Osman et al., 2001; McClean Screening Instrument Borderline Personality Disorder (MSI-BPD), Zanarini et al., 2003; Childhood Trauma Questionnaire/ Recent Trauma Questionnaire, Pennebaker and Susman, 1988) collated data on potential explanatory variables.

At the end of the survey, all participants (N=124) were invited to take part in an in-depth interview. We recruited twenty-six individuals (26/124). All twenty-six individuals had completed the cross-sectional survey during the first phase of the study. Demographic information related to the participants was captured during the cross-sectional survey. With lengthy waiting lists for specialist gender services, we were also keen to capture the experiences of individuals who are not currently attending specialist gender services for whatever reason. Community participants were recruited through information events for adults waiting for specialist services and through partnerships with trans and LGBT specific support groups and organisations (N=14). Interview participants total (N=40).

The proportion of individuals with autism traits in the service sample (34.6%), while in the community sample 14.3% of participants self-reported a previous autism diagnosis. The allocation to the autism trait group for participants who were attending services was based on the combined score of the three autism screening tools: AQ, EQ and RAADS-14. Community participants only completed a short demography questionnaire as part of their interview. In the absence of additional information related to autism traits, participants who described having an autism diagnosis based on a clinical diagnostic assessment were categorised as having autism traits. It is likely that this represents an underestimate of individuals in the community sample with autism traits as only self-report of a clinical diagnosis could be taken into account in the absence of autism screening tools.

Personal and Public Involvement (PPI)

Three experts-by-experience played a pivotal role in GIFTS - all had extensive experience of living with gender related distress and navigating specialist gender services in NI, and two of the three provided insight into the challenges of being both autistic and accessing services. They were also leading organisers of the Belfast Butterfly Club, Transpride NI and Trans-Derry. The issue of who can be called an expert-by-experience has been highlighted (McLaughlin, 2009). All experts by experience were actively involved in the trans community organisations in NI. They experienced anger and hostility towards them at times due to their involvement in the research. Travers et al (2013) describe this process as horizontal hostility, where individuals in marginalised communities damaged by trauma and exclusion enact similar patterns on each other. Experts by experience in GIFTS were very clear about their expertise based on their own lived experiences rather than acting as experts for a whole community.

Findings

- The study recorded a high prevalence of autistic traits (17.2%) among the gender dysphoric population (even when using the very stringent measure).
- Mental health problems, suicidality (57.7% high risk) and experience of multiple traumatic childhood events (52.9%) were common among these service users. Individuals who identified as transmale/ transfemale had 2.4 times the odds of having a high risk of suicidality compared to those who identify as male, female or non-binary. The result was statistically significant.
  Non-binary individuals had odds of 1.8 (95% CI: 0.3-11.7) for having depression and odds 4.5 (95% CI: 0.5 - 42.3) of having anxiety compared to those identifying as male. Participants who identified as female recorded an odds ratio of 10 (95%CI=1.2-82.7) for reporting three or more recent traumatic experiences.
- While there were no differences related to suicidality and recent trauma, individuals with autism traits had higher levels of anxiety and depression and were more likely to have experienced childhood traumatic events. Estimates of diagnosable mental health difficulties in autistic adults vary considerably, from as much as 84% (Stewart et al., 2006) in clinically referred populations to between 25-30% in epidemiological population studies or follow-up studies (Brugha et al., 2011; Hutton, 2008; Underwood et al., 2010). Overall, studies report high rates of anxiety and depression, often occurring in combination.
- There were clear differences in assigned-at-birth ratios between services, suggesting changes in who is accessing treatments.
- There was no difference between participants with autism traits and others in relation to demographic factors, waiting times for services and treatments received.
- Interviews highlighted that individuals felt that their authenticity – as transgender - was questioned by services, leading them to limit their trust of the experts and the selection process. Having a non-binary identity or multiple identities made the process of portraying an authentic identity much more difficult for them.

- Individuals attending services engaged in impression management strategies to convince staff of their need in order to access treatments. This included hiding their mental health difficulties to access services which left their mental health needs unmet. Individuals with autism traits engaged in camouflaging strategies to hide their autism traits which left them exhausted and struggling to function.
- The experience of gender services was dependent on the perceived authenticity of participants and was more negative for non-binary individuals. Service experience was highly dependent on timing of referral with those referred more recently having to wait longer for services. Overall individuals struggled to engage with expert systems as they frequently believed they had greater expertise themselves.

Conclusion

Throughout the duration of GIFTS there were a number of regional, national and global changes impacting on transgender healthcare provision. From a regional perspective the Northern Ireland provision related to specialist gender services changed from two functioning specialist gender services, one for adolescents and one for adults, to an adolescent service only, with hundreds of adults waiting over three years for the adult service (Transgender NI). Northern Ireland functioned without a devolved government from January 2017 to December 2019 and, while the Civil Service continued to operate, many decisions requiring ministerial approval were put on hold, impacting on future planning for health care provision.

A House of Commons Committee report in 2016 highlighted serious deficiencies in the quality, capacity and accessibility of gender identity services across Great Britain. Recent high-profile court cases against the Tavistock National Gender Identity Service (Tavistock and Portman NHS Trust, 2019) have received media attention and have polarised opinions related to how young people with gender related distress should be best managed.

From a global perspective gender dysphoria is still considered a psychiatric diagnosis by the current Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), but has recently been re-classified in the International Classification of Diseases (ICD-11) (World Health Organisation, 2019) under the category of sexual health. This has been in keeping with an international movement to de-pathologise gender related distress. GIFTS was not focused on societal perceptions of transgender individuals but explored the patient needs, authenticity and personhood of those seeking gender affirming treatments, those waiting and those living with gender incongruence.

Practice and Policy Implications

Autism screening and access to autism diagnostic assessments

Based on my findings that a considerable proportion of individuals with autism traits will seek help from Gender Identity services, it is important to offer screening for autism traits to all individuals attending such services. The three autism screening measures used in this study take minimal time to complete (and score) and provide a good basis for consultative engagement with the individual about whether access to a diagnostic assessment would be helpful. The RAADS-14 in particular consists of only one page and can be completed and scored very quickly. A discussion around autism traits as a challenge as well as an advantage could show acceptance of working holistically with the individual. Destigmatisation of autism traits and improved public education related to autism are needed to create a more inclusive society. Increased awareness of autism traits in primary services would allow timely access to diagnostic assessments if needed.

Systemic working in specialist gender services

Most specialist gender services are set up with a focus on explorative engagements requiring a high level of social and communication skills. Questions are often open ended, non-directive and meanings might be implied making the engagement potentially more challenging for persons with autism traits. The planned involvement of families and dedicated family interventions provided by both services could greatly enhance the experiences of young people and adults, while also supporting those closest to them in managing the treatment processes with their loved ones.

Mental health screening

While it remains unclear if increased anxiety and depression levels are based on availability and effectiveness of psychological or pharmacological treatments for participants without autism traits or the difficulty in assessing anxiety or depression in individuals with autism traits, this highlights a potential unmet need. All individuals, and particularly individuals with autism traits accessing specialist gender services should be offered screening for the presence co-existing mental health needs, in particular anxiety and depression. Mental health screening tools used in this study can be used for this purpose. If co-existing mental health needs are identified, individuals should be offered mental health specific supports alongside their gender affirming treatments. Co-existing mental health difficulties should not be viewed as criteria to exclude from specialist gender services, as gender affirming treatments often improve mental health.

Non-binary pathways

In the World Professional Association for Transgender Health (WPATH) guidance clear reference is made to non-binary identities (Coleman et al., 2012). DSM-5 guidance (American Psychiatric Association, 2013) makes clear reference to non-binary identities by highlighting in their criteria that to be of the other gender also includes some alternative form of gender and strong desire to be treated as the other gender also includes being treated as some alternative gender different from one`s birth assigned gender. These references of non-binary identities in clinical guidelines and diagnostic criteria should guide clinical services in the treatment of non-binary individuals.

Increasing visibility through information about non-binary pathways, for instance through making specific references in service information leaflets or service websites, would reduce the likelihood of individuals feeling that they have to present in binary ways to ensure easier access to services. This might include specific information about hormonal or surgical treatment options for non-binary individuals or non-binary representation at service information events. Having representation of non-binary options would also allow opportunities to gain more knowledge and understanding of the needs of non-binary individuals, which could inform future treatment options.

Pathway to Impact

This final project report will be shared with all the organisations who supported the study. Further distribution of findings through social media and community organisations will be supported by experts-by-experience involved in the study. Unfortunately various planned seminars had to be cancelled in light of the current pandemic, but webinars can be arranged in their place. A number of papers related to the study have already been published (Lehmann and Leavey, 2016; Lehmann and Leavey, 2019; Lehmann et al., 2020), with other papers in press.

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Relevant Logos

AffirmNI

Belfast Trans Resource Centre

Cara-Friend

common YOUTH.

Focus the identity trust

Supporting Transgender
And Intersex Individuals
And Their Families

the rainbow project

Promoting the Health and Wellbeing of LGB&T people in NI