

Gender Dysphoria and Autism Spectrum Disorders

Abstract

This Systematic map review report on empirical studies addressing autism spectrum disorders (ASD) and gender dysphoria (GD) to date. Forty-seven studies were included in the review which is a considerable increase of studies compared to earlier reviews within this scope. We report on these trends that show a significant increase in the number of studies within the past few years. The increased attention is welcome, but several challenges need to be addressed in future research. As this systematic map review reveals, most studies on this topic are conducted in the western world, and little is known about the role of culture, ethnicity, and religion.

Introduction

Over the past two decades, and especially in the last years, increased attention towards topics such as sexuality and gender-related issues have been observed in the autism research community. This attention has increased in a time of heightened focus and empowerment of the Lesbian, Gay, Bisexual, and Transgender (LGBT) movement.

Gender dysphoria (GD) refers to the mismatch between the physical sex of an individual and the experience of own gender. GD was introduced in the DSM-5(American Psychiatric Association, 2013), as a replacement for gender identity disorder (GID) in the DSM-IV-TR(American Psychiatric Association, 2000). In DSM-IV-TR, GID is recognized by cross-gender identification and distress with its biological sex. The prevalence of GD or GID have been reported to be as rare as 1:50,000 (Zucker and Lawrence 2009), compared to an incidence of 1 in 68 for ASD (Baio, 2012), causing the co-occurrence GD and ASD to be a rare condition. Research on the co-occurrence of GD and ASD have revealed that 7.8% of transgender individuals report a lifetime prevalence of ASD (De Vries et al., 2010; Glidden, Bouman, Jones, & Arcelus, 2016). On the other hand, Pasterski and colleagues found no such

Gender Dysphoria and Autism Spectrum Disorders

differences between transgender and the general population regarding ASD prevalence (Pasterski, Gilligan, & Curtis, 2014). Understanding the clinical features and the clinical relationship between GD and ASD is of great importance, and while there is an increasing number of studies conducted, more systematic reviews on this topic are needed to develop this growing field of research further.

The present study aims to give a thorough overview of, and map the available empirical research published in the field, as well as to report on critical variables such as types of designs commonly used, types of age cohorts and number of participants included in the various studies.

Methods

Literature search

The literature search was initiated March 2018 and terminated April 2018 by one of the authors (ANH). As the EMBASE database includes studies from 1946 and onwards we searched for studies published between 1946 to April 2018. A selection of broad databases covering publications from various disciplines were used to ensure a comprehensive search. The databases were the following; EMBASE, MEDLINE, PubMed, PsycINFO, and ERIC. An example search string (for EMBASE) including Boolean operators were as follows; Transsex* OR transgender OR gender dysphori* OR gender identity disorder* OR gender identit* OR sexual Ident* AND Pervasive develop* disorder* OR pdd OR pdd-nos OR pervasive developmental disorder not otherwise specified OR autis* OR Autism Spectrum Disorder* OR Asperger* OR asd. We also scanned studies used in previous reviews on the topic (Glidden, Bouman, Jones, & Arcelus, 2016; Van Der Miesen, Hurley, & De Vries, 2016; van Schalkwyk, Klingensmith, & Volkmar, 2015).

Inclusion and exclusion criteria

Any studies regardless of design that presented empirical information on any number of participants were included as long as the topic related to the terms Autism spectrum disorder and Gender dysphoria in the title and/or abstract. We included only studies that have been published in scientific journals. Hence, grey literature such as dissertations, presentations of posters and the like were not included in this review. As is customary, we did not regard narrative literature reviews or systematic reviews as empirical studies, so these were excluded after the title and abstract screening. As many studies include aspects related to for instance GD and autistic traits but not necessarily a firm diagnosis of the latter (or the former for that matter), we did not exclude studies where a diagnosis was not confirmed. No language restrictions were set according to Cochrane guidelines (Cochrane.org).

Screening and study selection

Articles were screened in two stages. First, both authors screened title and abstracts of the publications. In two instances uncertainty had to be decided through discussion that regarded two case studies published as letters to the editor. Both studies were included in the study. Two studies were excluded on the full-text screening stage as these were letters to the editor that did not contain any new empirical data (Bejerot, Humble, and Gardner, 2011; Bennett and Goodall, 2016). All finally included publications are noted with an asterisk in the reference list.

Criteria for including participant numbers

We only report on the actual number of participants included in the final analyses in the respective studies. This means that when a study published a total N and then a drop-out rate, we report on the number of participants that were included after drop-outs had been removed.

Gender Dysphoria and Autism Spectrum Disorders

This to give the best picture of the size of the study samples of which results are based upon. Further many studies, particularly case-control studies make use of control groups that typically are much larger than for instance the ASD group so that the number of ASD participants or suspected to have ASD are much lower than the amounts reported in this study. For example, in De Vries et al. (2010) seven out of 204 participants reached ASD cutoffs on the DISCO algorithm.

Analyses

Results from the studies are presented using frequency descriptive statistics. Also provided are overviews of type of study design and methods used, and what participants that were included in the studies. We also provide an attached Excel-spreadsheet with more detailed information regarding what journal the study was published in, the primary focus of the respective articles, main perspective (typically psychological), country of origin of participants, country of origin of study/authors. The frequency descriptive data show the trends in the amount of empirical studies published in the combined field of GD and ASD. We also provide data that show the various age cohorts of the publications.

Results

After removing duplicates, the search in the various databases resulted in 146 results. Two more studies were included after consulting with previously published systematic reviews, making the total number of results after initial searches to 148 publications. All 148 titles and abstracts were screened by both authors which led to the inclusion of 47 studies. Of these, 28 used quantitative methods and 19 used qualitative. The most used quantitative approach was case-control studies, whereas case-studies of one or few participants were the most common design among the qualitative approaches. Below are tables of the studies where *table 1* lists

Gender Dysphoria and Autism Spectrum Disorders

the qualitative publications and *table 2* lists the quantitative publications. The table gives an overview of authors and year of publication, type of study design and methods, participants included in the study, and age group in focus. Note that diagnosis is not necessarily confirmed in most cases but allude to the scope of the publication. For a more detailed overview of the latter and other study characteristics see the attached Excel-sheet.

[Table 1 and 2 in about here]

In terms of trend data that consider what year-cohort the publications have been published, a not surprising increase was found that shows a fast-growing field. An almost doubling of publications the past three and a quarter of years (2015-April 2018) compared to the five years (2010-2014) before.

[Figure 1 in about here]

As seen in *Figure 2* most publications include participants in adulthood. However, there is a spread of different age-cohorts represented in publications.

[Figure 2 in about here]

Discussion

This review summarizes the published empirical studies within the field of gender dysphoria and autism spectrum disorders. As revealed in the present mapping review, it is clear that there has been a marked increase in studies on the selected topic over the past two decades.

Gender Dysphoria and Autism Spectrum Disorders

Particularly, the past few years show a considerable rise in studies published in scientific journals. The increased focus on gender dysphoria, sexuality and ASD could be explained by the patterns observed in the general population, where changes in sexual attitudes have been massive over the past decades. It is plausible that internet and the technological revolution have allowed for a more natural exchange of lived experiences for those minorities with different sexualities, gender issues and also those with co-occurring ASD. This has led to less taboo, stigmatizing and more empowerment of these minorities, which the LGBT movement is a good example of. It is further essential to state that most studies in the present systematic map review are conducted in the western world, with some exceptions. While there has been a significant improvement in attitudes and the rights of sexual minorities, as new legislations are being made, there is still room for further improvement for sexual minorities also in the western world. In addition to factors such as resources, the reason for the overrepresentation of studies from the western world is due to different cultural and religious beliefs, and it will take time before we see studies on GD and ASD from a wide range of countries and areas of the world.

While there have been significant increases of studies conducted on ASD and GD, with increased quality in terms of scientific rigor, there is still much work to be done and significant challenges ahead. One of the prominent difficulties that researchers experience is that prevalence of ASD and GD isolated are low, and recruitment of individuals with the co-occurring conditions is a challenge. A possible way of action is for researchers across institutions, countries, and fields to make use of pooled samples. Also, the use of internet-based questionnaires may provide larger samples across countries and cultures (see for instance George & Stokes, 2018). Still, Turban and van Schalkwyk (2018) states that there currently is not enough evidence to indicate that GD is more prevalent in ASD or opposite. To shed more light on this, another valuable approach could be longitudinal studies following

Gender Dysphoria and Autism Spectrum Disorders

children onto adolescence and further into adulthood which will increase the understanding of the phenomena and give a better understanding regarding the proposed link between ASD and GD. Regarding methodology, both quantitative and qualitative approaches are essential. Especially, qualitative studies of lived experiences of individuals with co-occurring ASD and GD is vital to provide a better understanding and insight into these multifaceted experiences and conditions. This may in turn influence guidance practices and better prepare the help-apparatus for a group that are at risk for mental health problems.

Limitations

This review report on empirical studies that highlight both gender dysphoria and autism spectrum disorders. There are studies not included in this study that address both conditions. However, these studies typically investigate an array of psychiatric conditions including the two abovementioned and did not specifically note a GD and ASD focus. Further, no grey literature was searched for this study. Although no language restrictions were made it is, of course, possible that there are published papers in various languages that have not provided an English abstract. For those studies included that was in a different language with English abstract, authors were contacted to get missing information. However, in some cases, this was not provided.

Compliance with Ethical Standards:

This article does not contain any studies with human participants performed by any of the authors.

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Gender Dysphoria and Autism Spectrum Disorders

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Gender Dysphoria and Autism Spectrum Disorders

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Gender Dysphoria and Autism Spectrum Disorders

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