S.I.: GENDER AND AUTISM



Gender Dysphoria, Sexuality and Autism Spectrum Disorders: A Systematic Map Review

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Abstract

In this systematic map review, we aimed (1) at identifying studies including the co-occurrence of autism spectrum disorders (ASD) and gender dysphoria (GD) between 1946 and 2018, and (2) to present the papers included in this systematic map review to provide authors in the field of GD, sexuality and ASD with an important database of studies focusing on this very complex topic. The field is of emerging interest, as observed by the large increase of studies over the past decades, especially since 2015. However, future challenges are to be addressed in future studies.

Keywords ASD · Gender dysphoria · Identity disorder · Sexuality

Introduction

The term gender dysphoria (GD) is defined as a mismatch between the phenotypic sex of an individual and that person's perception of her/his own gender. GD was introduced in the latest revision of the American Psychiatric Association's classification system, DSM-5 (American Psychiatric Association 2013) as a replacement for the term gender identity disorder (GID) which had been used in the previous DSM-IV TR revision (American Psychiatric Association 2000). GID had been classified on the basis of cross-gender identification together with distress caused to the person by her/his biological sex, while GD does not require the person to be distressed by the disparity. Gender identity disorders

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are also in ICD-10 (World Health Organization 1992) characterized similar to GID in DSM-IV-TR. The recent ICD-11 uses the term gender incongruence to describe the same diagnosis (World Health Organization 2018). In this systematic map review we will for ease of interpretation use the term GD for both GID and GD.

In terms of prevalence, few studies have systematically measured the rate of GD in the general population. However, estimates on GD prevalence have previously been reported to be as rare as 1:50,000 (Zucker and Lawrence 2009). Recent studies have indicated that the prevalence of GD is increasing, and it is important to note that the prevalence of GD have been consistently reported to be lower in children relative to adolescents and adults (Zucker 2017). The maleto-female ratio of GD is consistently reporting a male predominance, especially in childhood studies of GD (Zucker 2017). According to a Center for Disease Control (CDC) report, the prevalence of ASD has increased massively over the past decades, specifically, from 1:68 to 1:59 (Baio 2012; Baio et al. 2018) Studies have previously reported that 7.8% of individuals with GD report a lifetime prevalence of ASD (De Vries et al. 2010).

Over the past two decades, and especially in the last years, an increased attention towards topics on sexuality and gender-related issues have been observed not only in the general population, but also 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. Understanding the complex



interplay between GD, sexuality and ASD is important, and calls for studies of the phenomenological and clinical presentation of this co-occurrence. Furthermore, it is a pressing need to understand whether or not the reported increased rate of ASD in GD compared to the general population is true, or if it is a representation of fallible research that might not take into account the breadth of symptoms that arise from the core deficits in ASD.

While these advantages will be important and define the future of the field, the current systematic review aims at mapping the current empirical research on the co-occurrence of GD and ASD. As such, it will include studies of ASD in samples of individuals with GD and also in the reverse condition. The underlying rationale is to make a systematic and extensive overview of published articles on this phenomena that can serve as an important database for researchers working on this topic.

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 the authors searched for studies published between 1946 and April 2018. A selection of broad databases covering publications from various disciplines was 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 is 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.

In addition to our own systematic review, we scanned for studies identified in previous reviews that had not been identified by our literature search (Glidden et al. 2016; Van Der Miesen et al. 2016; van Schalkwyk et al. 2015).

Inclusion and Exclusion Criteria

All studies, regardless of design or sample size, that presented empirical information were included providing that the terms Autism spectrum disorder and Gender dysphoria in the title, abstract and/or keywords. Studies were included only if they had been published in peer-reviewed scientific journals. 'Grey' literature such as dissertations, presentations of posters and the like were excluded. Purely narrative literature reviews and systematic reviews were excluded

after title and abstract screening. Many of the studies we have reviewed cover aspects of GD or GDI combined with autistic traits but with no confirmed clinical diagnoses. No language restrictions were set for the review in line with Cochrane guideline recommendations (http://www.Cochrane.org).

Screening and Study Selection

Articles were screened in two stages. First, two authors screened title and abstracts of the publications. Two studies that were included were published as 'letters to the editor' (Tateno et al. 2008, 2015). Both of these were included in our analysis Two further 'letters to the editor' studies were excluded at the full-text screening stage as they contained no new empirical data (Bejerot et al. 2011; Bennett and Goodall 2016). All of the publications that were included are noted with an asterisk in the reference list.

Criteria for Including Participant Numbers

Number of participants included in the final analyses are reported for the respective studies. When a study had reported a total N, then a drop-out rate, we report the number studied after drop-outs were excluded. This give the size of the study samples on which results are based. Many studies make use of large non-AD/ASD and non-GID/GD control groups that can be much larger than the groups of interest. In De Vries et al. (2010), for example, only seven of 204 participants, all of whom had been referred to a gender identity clinic, 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 the participants that were included in the studies. The authors 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 volume of empirical research published in the combined field of GD and ASD. We also tabulate data showing the age cohorts each study.

Results

After removing duplicates, the search in the various databases produced 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 two authors which led to the inclusion of 47 studies. Of these, 28 used quantitative methods and 19 used qualitative methods. 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 whereby Table 1 lists 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

Table 1 Published qualitative studies (N=19)

Authors and year published	Study type	Focus	No of cases and gender at birth	Age cohort	Country of study origin
Barnett and Maticka- Tyndale (2015)	Semi-structured internet-interview, thematic analysis	Sexual identities and experience	24 ASD	Adulthood	US
Dammasch (2014)	Case study	Co-occurence ASD and GD	1 ASD/GD	Adolescence	Germany
Fleta Zaragozano et al. (2005)	Case study	Co-occurence ASD and GD	1 ASD/GD	Childhood/adoles- cence	Spain
Gallucci et al. (2005)	Case study	Interaction gender identity disorder and Asperger syndrome	1 ASD/GD (male)	Adulthood	US
Jacobs et al. (2014)	Case study	Co-occurence ASD and GD	2 ASD/GD (male)	Adulthood	US
Kanbayashi (1997)	Case-study	Development of gender identity in an intelligent autistic male	1 ASD/GD (male)	Adulthood	Japan
Kobayashi (1991)	Case study	Psychosexual devel- opment of autistic adolescents	8 ASD	Childhood/adoles- cence	Japan
Kraemer et al. (2005)	Case study	Co-occurence Asperger syndrome and GD	1 ASD/GD (female)	Adulthood	Switzerland
Kuvalanka et al. (2017)	Case study caregiver report	Mothers experience of raising transgender child with ASD	3 Mothers of ASD/ GD	Childhood	US
Landen and Rasmus- sen (1997)	Case study	Co-occurence ASD and GD	1 ASD/GD (female)	Adolescence	Sweden
Lemaire et al. (2014)	Case study	Co-occurence ASD and GD	1 ASD/GD (female)	Adulthood	France
Mukaddes (2002)	Case study	Co-occurence ASD and GD	2 ASD/GD (males)	Childhood	Turkey
Parkinson (2014)	Case study	Co-occurence ASD and GD	2 ASD/GD (males)	Adulthood	Australia
Perera et al. (2003)	Case study	Co-occurence ASD, GD and OCD	1 ASD/GD (female)	Childhood	Sri Lanka
Tateno et al. (2011)	Case study	GD, PDD and AS	4 ASD/GD/PDD (3 male, 1 female)	Childhood/adoles- cence	Japan
Tateno et al. (2008)	Case study	Co-occurence ASD and GD	1 ASD/GD (male)	Childhood	Japan
Tateno et al. (2015)	Case study	Follow-up case study (Tatento et al. 2008)	1 ASD/GD (male)	Adolescence	Japan
Tissot (2009)		Sexual identity and ASD and school	7 ASD (6 male, 1 female)	Childhood/adoles- cence	UK
Williams et al. (1996)	Case study	Cross-gender preoccupation in ASD	2 ASD (male)	Childhood	US



Table 2 Published quantitative studies (N=28)

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Authors and year published	Study type	Focus	No of cases and gender at birth	Control group	Age cohort	Country of study origin
Abelson (1981)	Cohort study	Gender identity in children with autism	30 ASD (27 male, 3 female)	No	Childhood	USA
Akgul et al. (2018)	Case-control study	Autistic traits and executive functions in children and adolescents with GD	25 GD (13 male, 12 female)	50 sex and age matched controls	Childhood/adolescence	Turkey
Bejerot and Eriksson (2014)	Case-control study	Gender role, sexuality and empathizing/systemising	50 ASD (26 male, 24 female)	53	Adulthood	Sweden
Byers et al. (2013)	Online questionnaires	Sexual functioning in HFA/AS	129 ASD (61 male, 68 female)	No	Adulthood	USA
De Vries et al. (2010)	Cohort study	Incidence	204 GD suspected ASD (115 male, 89 female)	No	Childhood/adolescence	Netherlands
Dewinter et al. (2017)	Case-control study survey questionnaire	Sexual orientation, gender identity, romantic relationships	675 ASD (326 male, 349 female)	8064	Adolescence/adulthood Netherlands	Netherlands
Di Ceglie et al. (2014)	Case-control study (parent reported)	Empathizing and systemising in adolescents with GD	35 parents of GD adolescents (14 male, 21 female)	156	Adolescence	UK
Fisher et al. (2015)	Case-control	Paraphilia, GD, and autistic traits in indi- viduals with Klinefelter's syndrome	46 male Klinefelter with autistic traits	43	Adulthood	Italy
George and Stokes (2017)	Case—control study online survey questionnaire	Gender dysphoric traits, autistic traits and sexual orientation	309 ASD (90 male, 219 female)	261	Adulthood	Australia
George (2018)	Case—control study online survey questionnaire	Mental health in sexualand gender-minority groups in ASD	309 ASD (90 male, 219 female)	261	Adulthood	Australia
Gilmour et al. (2012)	Case-control study online questionnaires	Sexual attitudes and behaviours in adults with HFA	82 ASD (55 male, 27 female)	282	Adulthood	Canada
Heylens et al. (2018)	Cross sectional and clinical chart data	Prevalence of autistic traits in a GD population compared to controls	Cross sectional data: 63 GD (33 male, 30 female) Clinical chart data: 532 GD (351 male, 181 female)	1149	Adulthood	Belgium
Janssen et al. (2016)	Retrospective chart data	Co-occurence ASD and GD	492 ASD (409 male, 83 female)	1605	Childhood/adolescence	USA
Jones et al. (2011)	Case control online questionnaires	Autistic traits in people with GD	259 GD (198 male, 61 female)	2 controls: 174 Typically developing, 125 with ASD	Adolescence/adulthood	UK



Authors and year pub-	Study type	Focus	No of cases and gender	Control group	Age cohort	Country of s
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lished	Study type	Focus	No of cases and gender at birth	Control group	Age cohort	Country of study origin
Kaltiala-Heino et al. (2015)	Cohort study retrospective chart data	Adolescent applicants for sex reassignment and mental health	47 Sex reassignment applicants (6 male, 41 female)	No No	Adolescence	Finland
Kristensen and Broome (2015)	Cross sectional online questionnaire	Prevalence of trans identities and autistic traits	446 Trans identities (13 ASD) (279 male, 152 female, 15 not known)	No No	Adulthood	UK
May et al. (2017)	Case-control study	Gender variance in children and adolescents with ASD	176 ASD (136 male, 33 female)	1605	Childhood/adolescence	Australia
Nahata et al. (2017)	Retrospective clinical chart data	Mental health and therapy in transgender adoles- cents	79 Transgender (5 ASD: 3) male, 2 female)	No	Childhood/adolescence	USA
Pasterski et al. (2014)	Case-control	Co-occurence ASD and GD	91 GD (63 male, 28 female)	. 174	Adulthood	UK
Shumer et al. (2016)	Retrospective clinical chart data	Co-occurence Asperger syndrome and GD	39	No	Childhood/adolescence	USA
Shumer et al. (2015)	Nested case control study and comparison of SRS scores	Autistic traits in mothers and their children with GD	Nested Case with control group: 19 ASD (12 male, 7 female) Second sample children with high scores on SRS and GNC 94 GD (47 male, 47 female)	7.5	Adulthood	USA
Skagerberg et al. (2015)	Case-control study parent reports	Co-occurence ASD and GD	. 166	200	Childhood/adolescence	UK
Strang et al. (2017)	Interview, self report and parent report	Develop and test a measure of transgender fertility attitudes	Study 1: 25 transgender [17 non-autistic, 8 autistic (in ASD group 2 male, 6 female)] Study 2: 25 transgender (same group as in study), 26 parents	°N	Adolescence	USA
Strang et al. (2014)	Chart review study	Incidence GD, ASD and ADHD	116 Epilepsy/neurofibromatosis 126 ADHD, 147 ASD (123 male, 24 female)	1605	Childhood/adolescence	USA
van der Miesen et al. (2017)	Case-control study	Co-occurence ASD and GD	490 GD (248 male, 242 female)	2507 Typically developing 196 ASD (100 male, 96 female)	Childhood	Netherlands
VanderLaan et al. (2015a, b)	Clinical chart data	ASD traits and risk factors in GD children	49 GD (40 male, 9 female)	No	Childhood	Canada



Country of study origin Canada Canada Age cohort Childhood Childhood Control group 1930 ŝ 953 siblings (534 gender referred, 419 siblings) No of cases and gender 386 GD (304 male, 82 female) Obsessional interests in Obsessional interests GD children Feacher reports evaluation of psychometric Case-control study properties Study type VanderLaan et al. (2015a, Authors and year pub-Zucker et al. (2017)

(continued)

of the publication. For a more detailed overview of the latter and other study characteristics see the attached Excel-sheet.

In terms of trend data that consider the year-cohort of publication, a not surprising increase was found, indicating a fast-growing field. The number of publications almost doubling over the past three and a quarter of years (2015-April 2018), as compared to the preceding 5 years (2010–2014) (Fig. 1).

As seen in Fig. 2, the greatest proportion of publications reported on adult subjects. However, a spread of age-cohorts is represented.

Discussion

This systematic map review summarizes the published empirical studies within the field of gender dysphoria, sexuality and autism spectrum disorders. As revealed in the present review, it is clear that there has been a marked increase in studies on the selected topic over the past two decades. Particularly, the past few years show a considerable rise in studies published in scientific journals. The increased focus on GD, 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, especially social media, have allowed for a more natural exchange of lived experiences for those minorities with different sexualities, gender issues and also those with cooccurring 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 more conservative countries and regions where religion stands strong. However, as researchers, we need to keep pushing for global knowledge and acceptance of sexual minorities and disabilities to develop new insights. Increasing numbers of studies are being reported on ASD and GD, and these are of increasing quality and scientific rigor. There is still much work to be done and significant challenges lie ahead, and one of the most prominent challenges facing researchers in this area is that the prevalence of both ASD and GD is low, and recruitment of individuals with the co-occurring conditions is a challenge.



Fig. 1 Frequency of empirical articles published in scientific journals

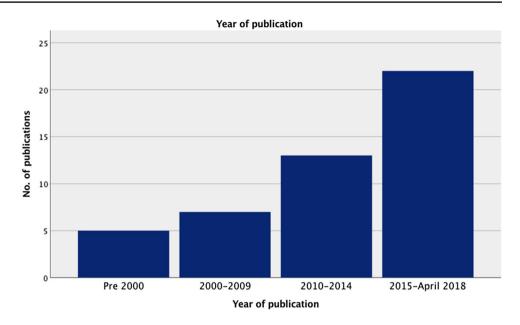
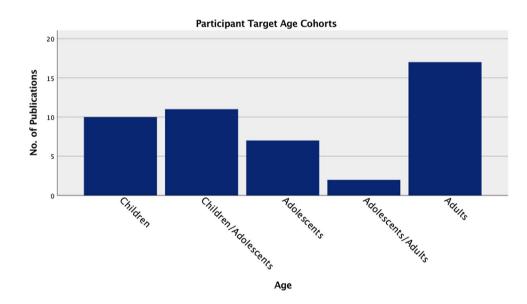


Fig. 2 Age-cohorts of participants in the publications. Children=0-12 years, Children/adolescents=0-18 years, Adolescents=13-18 years, Adolescents/adults=13 and above years, Adults=18 and above years



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 and Stokes 2018). Turban and van Schalkwyk (2018) state that there currently insufficient evidence to indicate whether GD is associated with ASD. One valuable approach could be longitudinal studies following children through adolescence and further into adulthood. This could increase our understanding of the phenomena, provide a better understanding of the proposed link between ASD and GD, and the extent to which they covary over time. 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.

This review reports on empirical studies that highlight both gender dysphoria and autism spectrum disorders. Some studies were not included that referred to both conditions. Typically, these were studies that investigated an array of psychiatric conditions including GD and ASD, but did not have these as a primary 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 any included study that was published



in a different language with an English abstract, authors were contacted to obtain missing information (four authors were contacted once). However, in some cases, this was not provided.

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Author Contributions RAØ and ANH conceptualized and designed the study, drafted the initial manuscript, carried out the analyses. RAØ, DVC, and ANH reviewed and revised the manuscript, and approved the submission of the final manuscript.

Compliance with Ethical Standards

Conflict of interest The authors have no conflicts of interest relevant to this article to disclose.

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

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