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Characteristics of children and adolescents referred to specialist gender services: a systematic review

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ABSTRACT

Background Increasing numbers of children/adolescents experiencing gender dysphoria/incongruence are being referred to specialist gender services. Services and practice guidelines are responding to these changes.

Aim This systematic review examines the numbers and characteristics of children/adolescents (under 18) referred to specialist gender or endocrinology services.

Methods Database searches were performed (April 2022), with results assessed independently by two reviewers. Peer-reviewed articles providing at least birth-registered sex or age at referral were included. Demographic, gender-related, mental health, neurodevelopmental conditions and adverse childhood experience data were extracted. A narrative approach to synthesis was used and where appropriate proportions were combined in a meta-analysis.

Results 143 studies from 131 articles across 17 countries were included. There was a twofold to threefold increase in the number of referrals and a steady increase in birth-registered females being referred. There is inconsistent collection and reporting of key data across many of the studies. Approximately 60% of children/adolescents referred to services had made steps to present themselves in their preferred gender. Just under 50% of studies reported data on depression and/or anxiety and under 20% reported data on other mental health issues and neurodevelopmental conditions. Changes in the characteristics of referrals over time were generally not reported.

Conclusions Services need to capture, assess and respond to the potentially co-occurring complexities of children/adolescents being referred to specialist gender and endocrine services. Agreement on the core characteristics for collection at referral/assessment would help to ensure services are capturing data as well as developing pathways to meet the needs of these children.

PROSPERO registration number CRD42021289659.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Increasing numbers of children and adolescents experiencing gender dysphoria/incongruence are being referred for care at specialist paediatric gender services.
⇒ Several countries have or are modifying referral and care pathways and provision, in response to both the reported increase in referral numbers and complexity of those referred.

WHAT THIS STUDY ADDS

⇒ There has been a twofold to threefold increase in the number of referrals and an increase in the ratio of birth-registered females to males referred to specialist paediatric gender services over time across countries.
⇒ Very few studies report data on gender status (self-reported gender identity, gender dysphoria/incongruence, age at onset and social transition) but from the limited data reported, approximately 60% of those referred were described as making steps to present themselves in their preferred gender.
⇒ Data published to date suggest that the presence of depression, anxiety, suicidality, self-harm, autism spectrum condition, attention deficit hyperactivity disorder and eating disorders may be higher in those referred to gender services than population estimates.

HOW THIS STUDY MIGHT AFFECT RESEARCH, POLICY OR PRACTICE

⇒ Specialist paediatric gender services need to respond to the potentially co-occuring complexities of children/adolescents being referred and agreement is needed on core characteristics for collection during assessment.

INTRODUCTION

Several countries have reported increasing numbers of children and adolescents experiencing gender dysphoria/incongruence being referred for care at specialist paediatric gender services over the last 10-15 years.[1 2] The research literature has also highlighted changes in the demographics of children being referred including reported mental health needs, neurodevelopmental conditions and psychosocial complexity.[3 4]

Specialist paediatric and adolescent gender services in several countries have modified or are currently modifying pathways and provision, partly in response to these reported trends.[5 6] This includes modifying referral criteria, processes and pathways as well as establishing new services.[7 8] In several countries, national guidelines and service specifications have been or are being reviewed and updated in response to concerns regarding the lack of high-quality evidence underpinning care for these children,[5 6 9 10] and the benefits, risks and long-term effects of medical intervention pathways.[11–16]

A better understanding of the numbers, characteristics and holistic needs of children and adolescents being referred to specialist gender services and how these may have changed over time would help to inform development in service provision

and referral and care pathways. This systematic review aims to answer the following questions:

1. What is the number of referrals to specialist gender identity/endocrinology services that provide healthcare for children/adolescents (age 0–18) experiencing gender dysphoria/incongruence and have these changed over time?
2. What are the characteristics of children/adolescents (age 0–18) referred to specialist gender/endocrinology services and have these changed over time?

METHODS

The review forms part of a linked series of systematic reviews examining the epidemiology, care pathways, outcomes and experiences of children and adolescents experiencing gender dysphoria/incongruence and is reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.[17] The systematic review protocol was registered on PROSPERO (CRD42021289659).[18]

Search strategy

A single search strategy was used to identify studies comprising two combined concepts: 'children', which included all terms for children and adolescents; and 'gender dysphoria', which included associated terms such as gender incongruence and gender-related distress, and gender identity terms including transgender, gender diverse and non-binary. MEDLINE, EMBASE and PsycINFO through OVID, CINAHL Complete through EBSCO and Web of Science (Social Science Citation Index) were searched (13-23 May 2021 and updated 27 April 2022).

Inclusion criteria

The review included peer-reviewed articles that reported at least birth-registered sex or age of children and/or adolescents at referral/assessment to paediatric or adolescent gender/endocrinology services (table 1).

Selection process

The results of the database and other searches were uploaded to Covidence[19] and screened independently by two reviewers. Full texts for potentially relevant articles were retrieved and reviewed against the inclusion criteria by two reviewers independently. Disagreements were resolved through discussion and the inclusion of a third reviewer.

Table 1 Inclusion and exclusion criteria

Population	Children and adolescents (age 0–18) referred to paediatric or adolescent gender service or paediatric or adolescent endocrinology service that provides specialist gender-related healthcare. Articles reporting on child or adolescent populations or the combined population of children and adolescents were included. Mixed populations of adolescents and adults were included if referred to child or adolescent gender service, for example, some services provide healthcare to age 24; or where data are reported separately for all-age services. Studies of other selected subsamples were excluded, for example, those eligible for or receiving treatment, one gender group, studies recruiting a specific or convenience sample.
Comparator	Any or none.
Variables	Article reports as a minimum the birth-registered sex and/or age of the referred population. Studies reporting data from the time of referral or initial assessment were included.
Study design	Studies of any design or articles reporting data from gender services. Systematic or other literature reviews were excluded.
Publication	Published in the English language in a peer-reviewed journal. Conference abstracts and letters were excluded.

Data extraction

Data on study and population characteristics were extracted into a prepiloted template by one reviewer and checked by another. Data were extracted from graphs using the plot digitizer tool (https://plotdigitizer.com/). With reference to the literature and input from expert advisors, key demographics, gender, mental health, neurodevelopmental conditions and psychosocial characteristics were extracted. Study quality was not formally assessed.

Synthesis

A narrative approach to synthesis was used and where feasible proportions were combined in a random effects meta-analysis using metaprop (Stata V.18) with variances stabilised using the Freeman-Tukey double arcsine transformation.[20] A line graph was used to plot referrals and a scatter plot for birth-registered sex ratios over time by country. Where multiple studies reported data over time, a single study was selected with the largest study period and/or which represented the largest or most representative service within that country. For countries where there were no studies reporting changes over time in birth-registered sex ratios, the mid-point from studies reporting figures across years was used. The synthesis was performed by one reviewer and second-checked by another.

RESULTS

Our searches yielded 28 147 records, 3181 of which were identified as potentially relevant for the linked series of systematic reviews, and for which full texts were reviewed. From these, there were 143 studies from 131 papers that met the inclusion criteria for this review (figure 1; online supplemental table S2).

Studies reported data from Canada (n=35), US (n=34), Netherlands (n=26), UK (n=16), Australia (n=8), Germany (n=6), Finland (n=4), Italy (n=3), Belgium (n=2), Spain (n=2) and single studies from Brazil, Denmark, Israel, Norway, Sweden, Scotland and Switzerland (online supplemental table S3). There were 4 linked articles and 10 multiple country studies which are included in the individual country summaries. Data were reported from 1972 to 2021 with many samples overlapping from the same service within each country, although more data were reported from 2000 onwards (online supplemental table S4).

Demographics

The number of referrals over time was reported for 11 countries (figure 2).[2 21–26] Around 5–6 years into the data presented by year in the individual studies there is a sharp increase (twofold to threefold) in referral numbers across all countries except the Netherlands which started to increase in 2011[25] and Denmark which only had 2 years of data.[2]

There was a mixture of child and/or adolescent data presented across countries with the average age of children being 7/8 and adolescents 14–17 (online supplemental table S3). The combined child and adolescent data showed mixed findings, with a group of studies conducted relatively early having ages around 10/11,[27–30] and later studies of around 13–16, which is more closely aligned to studies with adolescent samples. This indicates a potential increase in the number of adolescents within the combined samples.

Over time, there is generally an increase in the ratio of birth-registered females to males being referred to child and adolescent gender services across countries

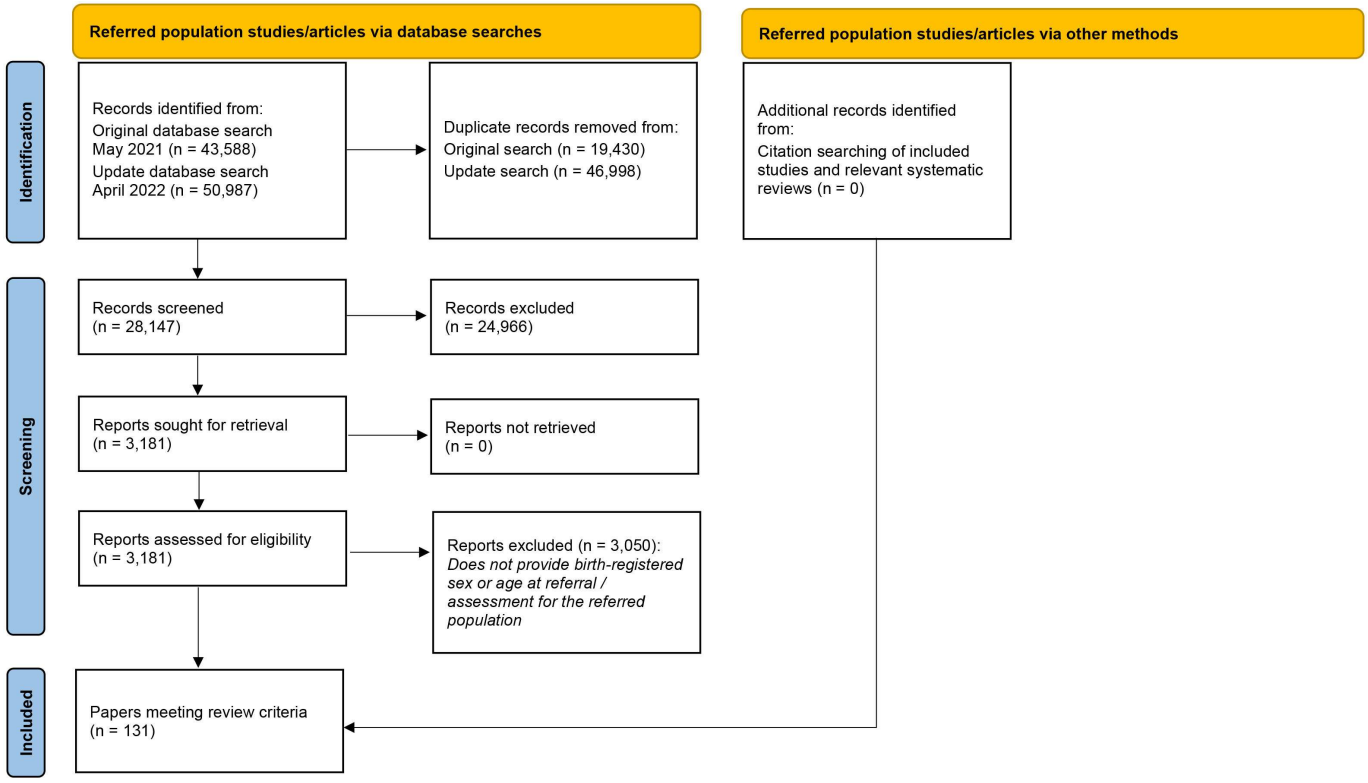

Figure 1 Study flow diagram.

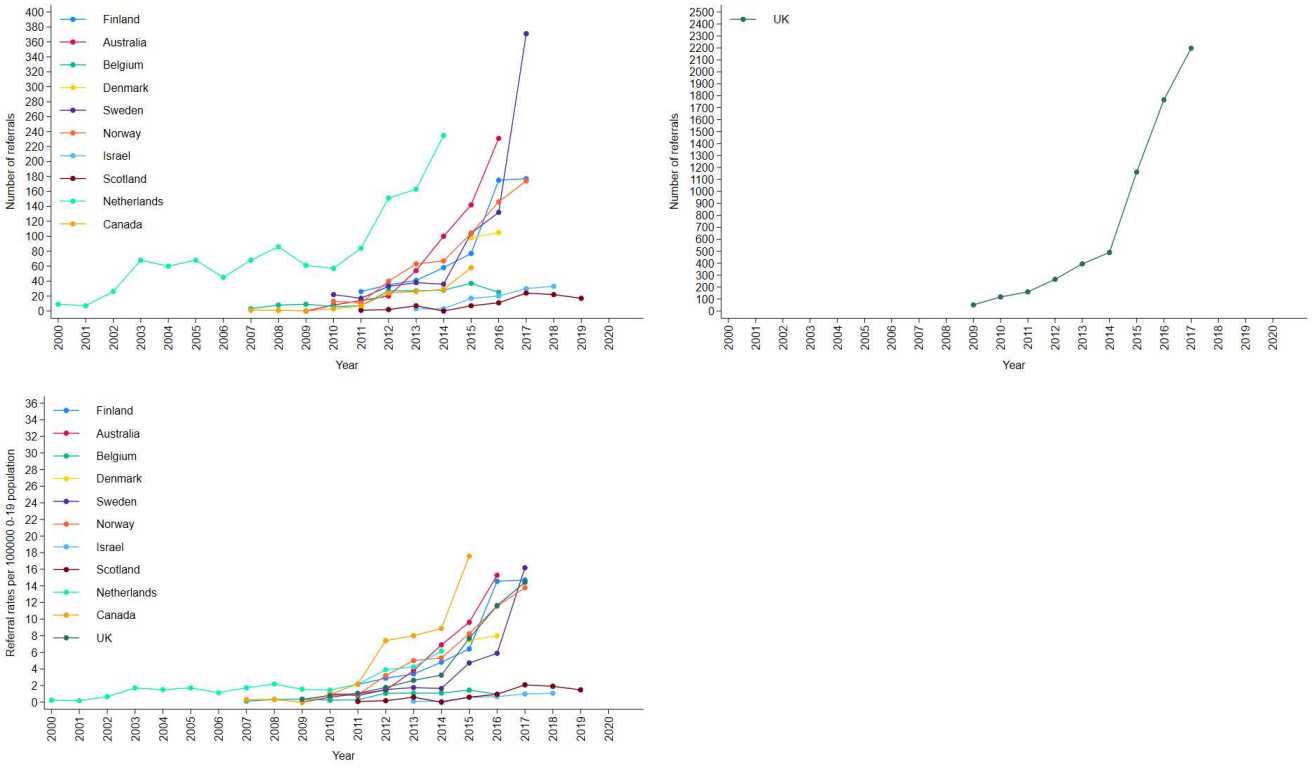

Figure 2 The number of referrals over time by country.

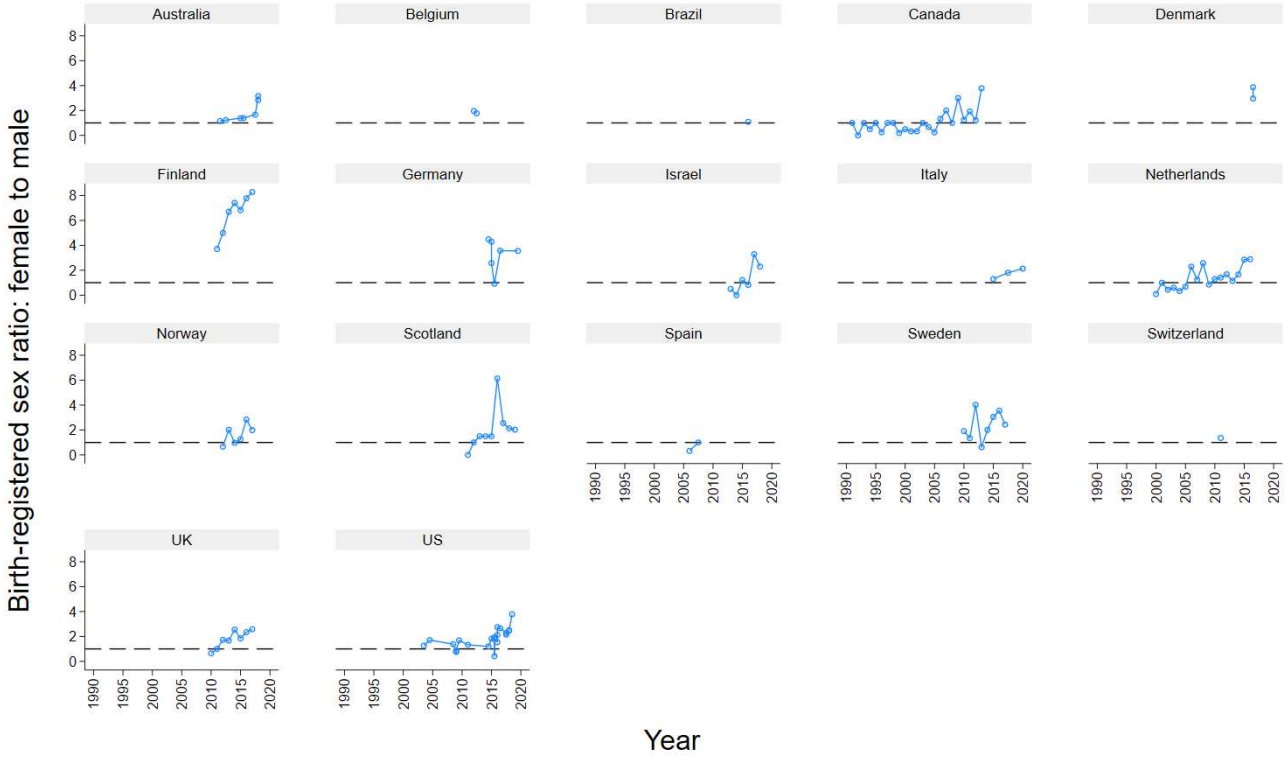

Figure 3 The ratio of birth-registered females to males being referred to child and adolescent gender services by country.

(figure 3).[2 3 7 8 21 22 24 26 31–70] There is no clear sudden increase but more of a steady increase over time; however, Finland reported a higher ratio throughout. Given the number of referrals is relatively low in some services/countries, there are fluctuations in the data with the ratios increasing one year and decreasing the next. Three studies in the Netherlands reported data by child/adolescent groupings and found that the ratio of birth-registered females to males was below 1 in children (indicating more birth-registered males compared with females) and at or above 1 in adolescents (indicating more birth-registered females compared with males) and approximately twice as high as the child ratios (online supplemental table S3).[25 28 71] Similar results were found in the only Canadian study that disaggregated data in 4-yearly blocks.[72]

Gender characteristics

There were country differences in reporting how the children/adolescents had defined their gender identity (online supplemental table S3). Across most studies, self-reported gender identity was either not reported or inconsistently reported. Of those studies reporting the proportion of children/adolescents identifying as non-binary, estimates ranged from 0% to 19%.[33 34 40 46 53 54 56 58–61 64 67 73–80]

Data on diagnosis of gender dysphoria (DSM-5) or gender identity disorder (DSM-4) were reported in 65 studies with reported proportions ranging from 29% to 100%, with 52 studies including over 70% (and 64 including over 50%) experiencing gender dysphoria/incongruence (online supplemental table S3). Gender dysphoria/incongruence was assessed usually by diagnostic interview but occasionally using a gender identity/dysphoria scale. Some studies had an explicit inclusion criterion of meeting diagnostic criteria for gender dysphoria or gender identity disorder (or subthreshold) whereas others included the full referred population.

Eleven studies reported the onset of the experience of gender incongruence (n=6)[32 38 67 70 81 82] or gender dysphoria (n=5).[34 45 82–84] For gender dysphoria, two studies reported mean/median ages which were approximately 7/8 (ranges 1–17)[34 83] and three studies reported the percentages in each age group, but they found different results.[45 82 84] For gender incongruence, three studies reported mean/median ages which were approximately 8–10 (ranges 5–15)[38 67 81] and three studies reported the percentages in each age group with two finding larger percentages in the under 8 group[32 70] but one finding a higher percentage in the 12+ category.[82]

Nineteen studies reported social transition data from seven countries.[3 7 38 42 44 48 55 56 67 74 76 81 84–90] The US reported higher proportions of social transition (combined 77%, 95% CI 70% to 90%) compared with most other countries (combined 59%, 95% CI 52% to 66%). There is no consensus on the definition of social transition and the studies included a wide range of changes. Estimates of changing name (n=6) ranged from 48% to 96%, pronouns (n=1) at 61% and changing appearance (n=2) between 75% and 99%. A single study reported details of where transitions took place and reported 61% home, 59% school and 7% online.[7] There were five studies reporting the data split by birth-registered sex.[84 85 88 89] All but one study found higher estimates of full social transition and all studies for name change in birth-registered females compared with males. The average age of social transition was approximately 14 (range 4–28, n=4) and two studies reported age bands (28% in the 6–11 and 81% in the >15 categories).

Mental health

Eating disorders

There were 16 (11%) studies from eight countries reporting eating disorder data for the referred population, with data reported from 1998 to 2019.[3 8 24 26 34 38 58 75 84 87 88 91–95] The combined estimate was 5% (95% CI 2% to 8%) with the lowest estimate of 0% (children) and highest of 23.4% (objective binge eating from a self-report scale). One study reported the data split by age groups and found all cases of eating disorders were identified in the age group of 12–18 years (16%) and 0 in the age group of 5–11 years.[84] Seven studies split data by birth-registered sex with inconsistent findings.[24 34 58 84 87 92 95] There was no consistency in the way in which eating disorders were recorded with some reporting any eating disorder and others a single type of eating disorder, a mixture of eating disorder symptoms, clinical diagnoses, those receiving psychiatric help for eating disorders, or it was unclear. Those reporting eating disorders using clinical diagnoses generally found lower estimates compared with those including symptomology alone or in addition (5.2% diagnosed and 15.5% when also including symptoms) (online supplemental figure S1).[87]

Suicide and/or self-harm

There were 39 (27%) studies from 11 countries reporting data on suicide attempts and/or self-harm of the referred population, with data recorded from 1976 to 2021. The combined estimate for suicide attempts was 14% (95% CI 11% to 17%, range 9%–30%, n=16), self-harm was 29% (95% CI 23% to 35%, range 8%–56%, n=14) and suicide/self-harm together reported by parents/carers was 23% (95% CI 8% to 41%, range 7%–45%, n=5) and children/adolescents was 34% (95% CI 24% to 44%, range 21%–45%, n=5); highlighting differences between parent/carer and child/adolescent reported measures. Sixteen studies explored differences in attempts of suicide (n=11), self-harm (n=6) or combined (n=3) by birth registered sex.[24 34 38 45 51 58 75 84 85 89 92 96 97] Of those studies, the majority found higher estimates of suicide attempts and/or self-harm in birth-registered females compared with males. Six studies explored differences in suicide attempts and/or self-harm by age groups, with estimates generally higher in older age categories.[41 75 81 84 97 98] Two studies explored differences in suicide attempts and/or self-harm over time in the referred populations.[35 89] One found no trend over time[35] and the other found a reduction in suicide attempts in 2015 (8.6%) compared with 2012 (13.3%).[89]

There were 30 (21%) studies from 10 countries reporting data on suicide and/or self-harm ideation, with data recorded from 2002 to 2021. The combined estimate for suicide ideation was 39% (95% CI 30% to 48%, range 10%–87%, n=17) and suicide/self-harm ideation together for parents/carers was 26% (95% CI 19% to 33%, range 19%–36%, n=5) and children/adolescents was 41% (95% CI 32% to 51%, range 10%–78%, n=11); again, highlighting differences between parent/carer and child/adolescent reports. Two studies reported self-harm ideation and estimates were 4.1% and 14.4%.[84 97] There were differences in the recording of suicide ideation as some studies reported any history and others reported current ideation only; one study reported both figures and found a marked difference (history 47.3% and current ideation 12%).[81] Of the seven studies reporting suicide ideation separately, four found higher estimates in birth-registered females compared with males,[24 34 45 85] two found the opposite[58 84] and one found similar figures.[51] Both studies reporting self-harm ideation found higher estimates in birth-registered males compared with females.[84 97] There were mixed findings in the four studies combining suicide and self-harm ideation and differences between parent/carer and child/adolescent reports.[50 96] Five studies explored differences in suicide and/or self-harm ideation by age groups and generally estimates were higher in older age categories.[41 81 84 97 98]

Depression and/or anxiety

There were 63 (44%) studies from 13 countries reporting data for depression and/or anxiety in the referred population, with data recorded from 1980 to 2021. There were eight studies only reporting data in continuous form (mean and SD) and there were different measures used, so it was not possible to synthesise.[30 42 43 47 99–102] The combined estimate for depression was 38% (95% CI 31% to 45%, range 3%–78%, n=32), for anxiety was 38% (95% CI 31% to 46%, range 8%–100%, n=28) and depression/anxiety together reported by parents/carers was 48% (95% CI 39% to 56%, range 26%–75%, n=15) and children/adolescents was 44% (95% CI 36% to 52%, range 28%–66%, n=13).

Twenty-eight studies explored differences in depression (n=16),[24 34 38 50 51 58 82 84 85 89 90 92 94 95 103 104] anxiety (n=11)[51 58 82 84 85 89 92 94 95 103] or combined (n=12)[23 28 36 40 105–108] by birth-registered sex, the majority reporting higher estimates of depression and anxiety in birth-registered females compared with males. There were six studies exploring differences by age groups.[28 81 84 97 105] Four focused on both depression and anxiety and three found higher estimates in older ages[28 105] with the other finding no significant difference.[97] There were two studies each looking at depression and anxiety separately and much higher estimates for depression were seen in adolescents (over 12) compared with children, whereas the estimates for anxiety were similar across age groups or slightly higher in adolescents.[81 84]

Neurodevelopmental conditions

The combined estimate of autism spectrum condition (ASC) was 9% (95% CI 6% to 11%, range 0%–26%, n=26, nine countries, data range 1998–2019). One study reported data separately for 2012 and 2015 and demonstrated an increase from 1.8% to 15.1%[89]; no other study reported data broken down over time. It was generally unclear how ASC was defined in each study, where it was reported it included signs or traits, clinical diagnosis or current intervention due to ASC. Two studies reported the data split by age groups,[81 109] one found similar estimates of ASC in under 15s and 15+ (6%)[81] and the other a higher percentage of adolescents with ASC compared with children (9% vs 6%).[109] Seventeen studies split data by birth-registered sex, but the results were inconsistent. One of these studies reported data separately for 2 years and found changes over time (birth-registered females vs males: 2012: 10.4% vs 20.0% and 2015: 15.4% vs 14.6%) (online supplemental figure S1).[89]

The combined estimate of attention deficit hyperactivity discorder (ADHD) was 10% (95% CI 7% to 13%, range 2.5%–27%, n=20, nine countries, data range 1998–2021). Fourteen studies split the data by birth-registered sex, 12 of them found a higher percentage of birth-registered males with ADHD compared with females[3 8 26 31 34 40 51 55 66 68 75 82 84 85 88 91 92] and 2 finding the opposite relationship.[24 103] Across studies, the estimate of ADHD was 14% (95% CI 8% to 20%) for birth-registered males and 6% (95% CI 3% to 9%) for birth-registered females.

Adverse childhood experiences

There were relatively few studies reporting data on the different categories referred to as adverse childhood experiences (ACES) (n=15, 10%).[3 8 32 45 46 48 56 62 82–84 86 89 91 95] Eight studies reported data on physical (n=3),[8 32 91] emotional (n=1)[8] or sexual (n=4) abuse,[8 32 82 91] and neglect or abuse or neglect alone (n=6). Combined neglect or abuse figures were reported in four studies (range 11.1%–67.4%)[45 56 84 89] and neglect alone in two studies (10.5% and 11.4%).[8 32] Physical abuse estimates ranged from 15.2% to 20%, sexual abuse from 5.2% to 19% and emotional abuse was assessed in a single study (13.9%). Parental mental illness or substance misuse was reported in two studies and maternal estimates were higher (52.6% and 49.4%) than paternal (38% in both studies).[8 32] Two studies reported data on exposure to domestic violence (22.8% and 24.6%).[8 32] Loss of a parent through abandonment was reported in 10 studies with 5 reporting adoption (range 0.9%–8.2%),[3 45 48 62 83] 6 foster care (range 1.1%–12.3%)[8 32 46 48 83 84] and 2 children's homes (5.3% and 0.5%).[84 86] Two studies reported data for those experiencing death or permanent hospitalisation of a parent (8.4% and 19%).[8 95]

DISCUSSION

This systematic review found that there has been a twofold to threefold increase in the number of referrals to specialist paediatric gender/endocrinology services over time across countries. An increase in the ratio of birth-registered females to males was also observed. Although coexisting complexity was reported in fewer studies, the presence of ASC, ADHD, anxiety, depression, suicidality, self-harm, eating disorders and ACES appears higher than seen in the general population of children and adolescents.[110–113]

There was limited data reported to allow patterns to be explored in birth-registered sex ratios by child/adolescent groupings; however, data from the Netherlands (1972–2016) suggest the increase in the ratio of females to males was only in adolescents. More recent UK data (2017–2020) reported more females than males for children and adolescents but considerably higher ratios in adolescents.[114] Very few studies reported data on gender characteristics but from the limited social transition data reported, approximately 60% of those referred to gender services had made steps to present themselves in their preferred gender.

For mental health, the largest number of studies reported data on depression and/or anxiety (<50% of the studies), with most other mental health outcomes reported in <20%. Frequency of mental health issues has been found to be similar to other systematic/scoping reviews of this population.[4 115–119] Co-occurrence of depression and anxiety, and of suicidality and/or self-harm appear to be considerably higher in children and adolescents experiencing gender dysphoria/incongruence compared with population estimates,[110–112] and children/adolescents were consistently reporting higher frequencies of self-harm/suicide than their parents. Eating disorders may be slightly higher than population estimates, although no clear conclusion can be drawn due to heterogeneity in measurement.[113] Less research focus has been given to those with eating issues among children and adolescents experiencing gender dysphoria or incongruence, which is reported to affect around 22% of children/adolescents in the wider population.[120]

Frequency of ASC was found to be similar to other systematic reviews and may also be higher than population estimates, supporting current guidance to screen for ASC in specialist gender services.[5 10] However, robust research is needed to confirm this and to assess levels of ADHD in this population which has not been adequately explored to date. This review indicates that rates of ADHD may be equal to those of ASC; however, issues with diagnosis must be considered.

This review indicates that the majority of studies have not routinely measured or recorded the presence of ACES in the histories and experiences of children and adolescents being referred to paediatric gender services so there is limited data despite the wider research indicating that gender-diverse youth and adults have experienced high rates of childhood adversity.[121–125] It is not possible for this review to speculate as to the relationship between ACES and the experience of gender-related distress in children and adolescents, but the results indicate that this is another important area in which systematic collection of data, at referral and across pathways of care can support care.

Strengths and limitations

Strengths include a published protocol with robust search strategies and comprehensive synthesis. As searches were conducted to April 2022 this review does not include more recently published studies; as this is a rapidly involving area this is a limitation.

Caution should be taken when interpreting any of the pooled estimates as they represent data for a wide period of time, reported data averaged over a large number of years, included often overlapping samples from the same service, and often discrepancies in the individual studies between the referred numbers and those included in the summaries of characteristics. Additionally, different measures were used to assess mental health outcomes, for example, any diagnosis of an eating disorder versus a single symptom such as binge eating, and inclusion of historical difficulties, for example, self-harm ever versus current self-harm.

As there were multiple studies in some countries reporting referrals by year, a single study was selected with the largest study period and/or which represented the largest or most representative service. This could have influenced the findings of referral patterns. It was not possible to make inferences about changes over time for most characteristics explored due to overlapping samples and data being reported over large time periods in individual studies. There were some studies that did not report changes over time in the ratio of birth-registered females to males hence the mid-point from studies reporting figures across years was used. This may have artificially created trends in the data as there were often overlapping samples from the same service that are likely to include the same individuals multiple times. Despite these caveats, the results do show similar trends in the ratios to those studies reporting data split by year.

Conclusions

There has been a twofold to threefold increase in referrals to specialist gender services for children/adolescents across many countries. These children/adolescents show higher than expected levels of ASC, ADHD, anxiety, depression, eating disorders, suicidality, self-harm and adverse childhood experiences. Agreement of core characteristics for collection at referral/assessment would help to ensure services measure key outcomes and enable them to develop to meet the needs of these children and adolescents. Services need to assess and respond to any co-occurring needs and complexities.

Contributors LF, CEH, TL and JT contributed to the conception of this review. LF, RH, CEH and JT contributed to screening and selection. CEH and JT completed data extraction and synthesis and drafted the manuscript. LF, RH, CEH, TL and JT contributed to data and synthesis interpretation. All authors reviewed and approved

the manuscript prior to submission. CEH accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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Patient consent for publication Not applicable.

Provenance and peer review Commissioned; externally peer reviewed.

Data availability statement Data sharing is not applicable as no datasets were generated and/or analysed for this study.

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