The Evolution of the Diagnosis of Gender Dysphoria

Prevalence, co-occurring psychiatric diagnoses and mortality from suicide

[AR: See also further clarification, attached at the end of this report, of the commenton the OR of 4.8 in Table 2.
The clarification was obtained from Peter Salmi (one of the Authors)]

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Preface

The National Board of Health and Welfare has more closely mapped the development and prevalence of diagnosed gender dysphoria in the population. In this report, the National Board of Health and Welfare has taken into account co-occurring psychiatric diagnoses, self-harm behavior (including suicide attempts) and suicide mortality among people with gender dysphoria. The report is primarily aimed at the profession that faces people with gender dysphoria.

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Gender Dysphoria

A person with gender dysphoria has a pronounced experience of gender identity that does not match the sex recorded at birth. The experience often results in suffering.

Gender dysphoria is investigated by psychiatric specialist teams consisting of a number of professionals including psychiatrists, psychologists, and social welfare officers. The investigation has as an important goal: to establish whether the person suffers from true gender dysphoria or whether other reasons better explain the experience of gender identity not matching the recorded sex.

Currently three diagnostic codes are used for gender dysphoria. During the assessment, ICD code F64.9 is used as an unspecified (preliminary) gender identity disorder diagnosis. If an assessment confirms transsexualism, then the established gender dysphoria diagnosis F64.0 is made. A person who is non-binary, that is, identifies as neither male nor female, can receive the diagnostic code F64.8.

If any of the gender dysphoria diagnoses have been made, affirmative treatment can be started. In affirmative treatment, an endeavor is made to alleviate suffering by better adapting the body to the gender identity. Treatment measures may include, for example, hormone therapy and gender-affirming surgery. However, it is only in the case of an established diagnosis (i.e. transsexualism) that irreversible gender-affirming treatment may be relevant. However, in other gender dysphoria diagnoses, reversible hormone therapy may be relevant for some, in order to prevent unwanted puberty development.

In recent years, there has been an increase in people who are diagnosed with gender dysphoria in the population.[1] The increase applies especially to children and young people. A recently published report, the State's Preparation for Medical and Social Evaluation (SBU), shows major knowledge gaps regarding, for example, the reasons for the development of gender dysphoria and knowledge gaps of various aspects of gender-affirming treatment. [2]

In this report, the National Board of Health and Welfare presents a detailed report of the prevalence of gender dysphoria diagnoses and how the prevalence of diagnoses has changed over time. In this report, the National Board of Health has also taken into account co-occurring psychiatric diagnoses, self-harm behavior, and suicide mortality among persons with gender dysphoria. The results are based on individual patient data that are reported to the National Board of Health national register.

[1] The development of the diagnosis of gender dysphoria in Sweden. Social Agency, 2017.

[2] Gender dysphoria in children and adolescents. SBU, 2019.

Frequency

Prevalence

In 2018, a total of 5,841 people (0.06% of the population) had some gender dysphoria diagnosis (F64) in Sweden. Of these, 4,326 (0.04% of the population) had a confirmed diagnosis (F64.0), and 574 others had a preliminary gender dysphoria diagnosis, which is used, for example, when a person identifies as non-binary (F64.8).

As the number of people seeking help for gender dysphoria increases, and after investigation ultimately receive a preliminary gender dysphoria diagnosis, the number of people with a confirmed diagnosis is likely to increase in the long term when investigations are completed. Figure 1 shows this development. The diagnosis F64.8 has also increased over time (not separately reported in figures but included under F64 which includes all gender dysphoria diagnoses).

In a separate analysis, the National Board of Health estimates that around 70-80% receive a fixed diagnosis (i.e., transsexualism) after a preliminary gender dysphoria diagnosis.

Figure 1. Prevalence of Gender Dysphoria Since 1998

Prevalence of subjects diagnosed with gender dysphoria since 1998 among registered citizens of Sweden. The sex is registered at birth.

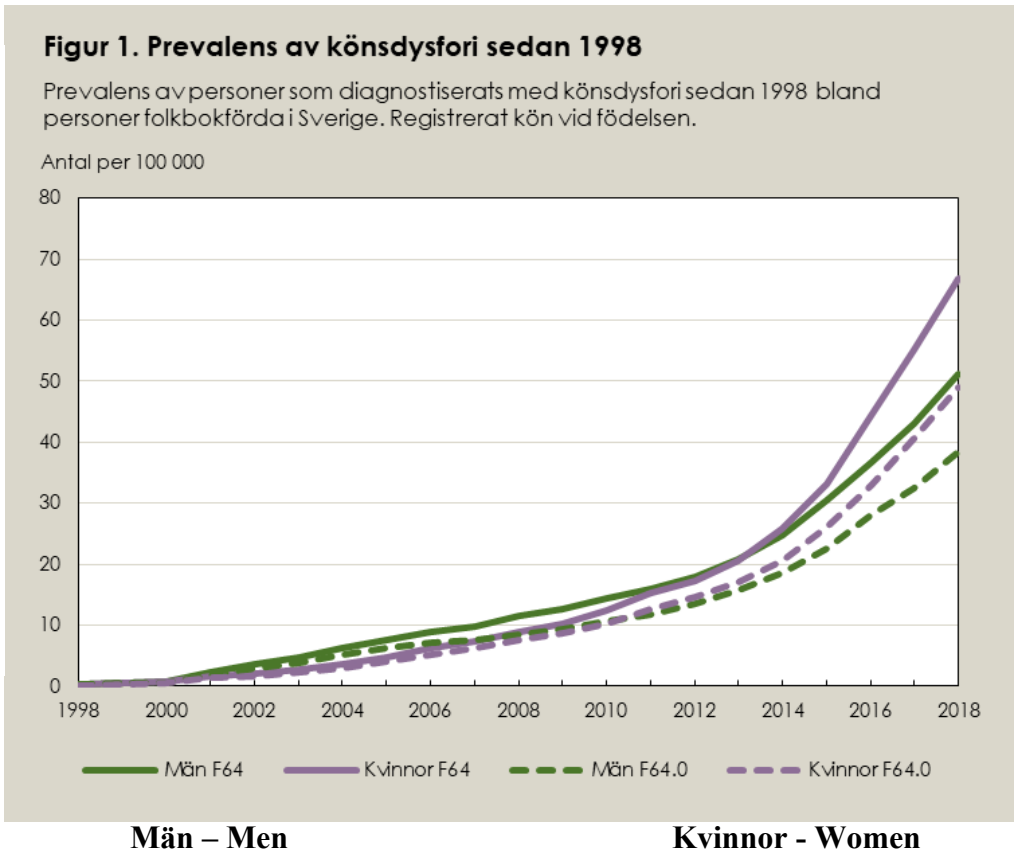
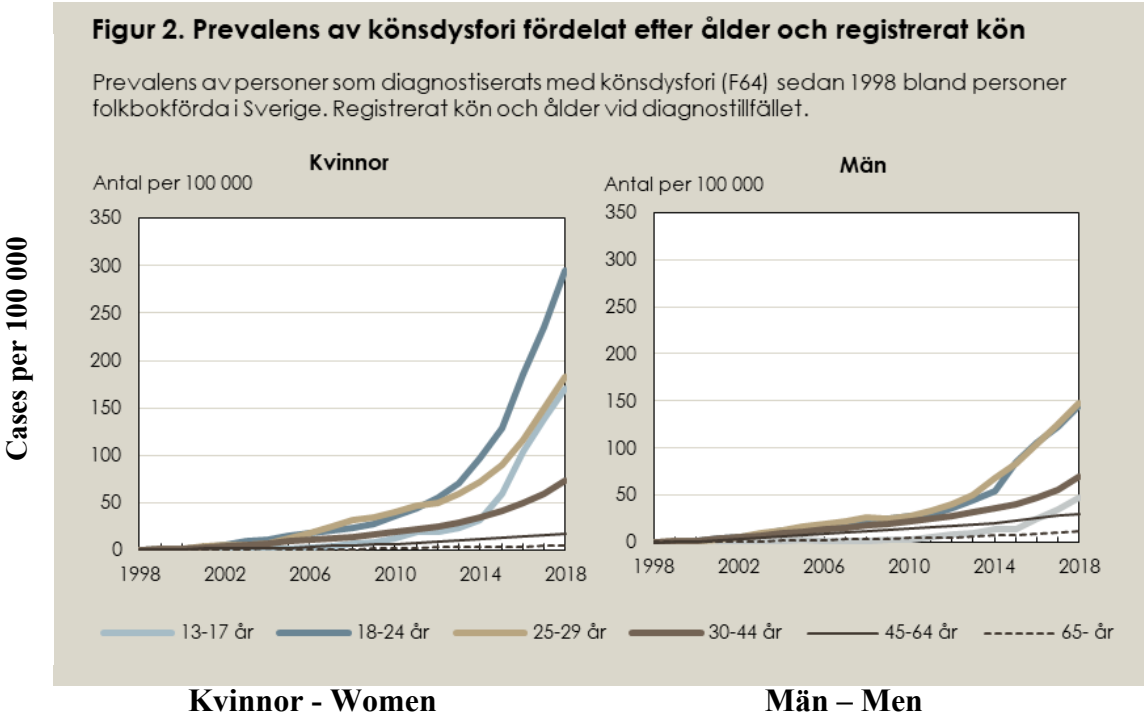


Figure 2 shows the rates of gender dysphoria diagnoses by year, tracked overtime and broken by age group. The prevalence of diagnoses has increased most among younger people, both those registered as males and females at birth. There has also been a clear increase among children 13–17 years of age who are registered as female as birth.

Figure 2. Prevalence of Gender Dysphoria by Age and Registered Sex

Prevalence of persons diagnosed with gender dysphoria (F64) since 1998 among registered citizens of Sweden. The sex and age are registered at the time of diagnosis.



Cases per 100 000

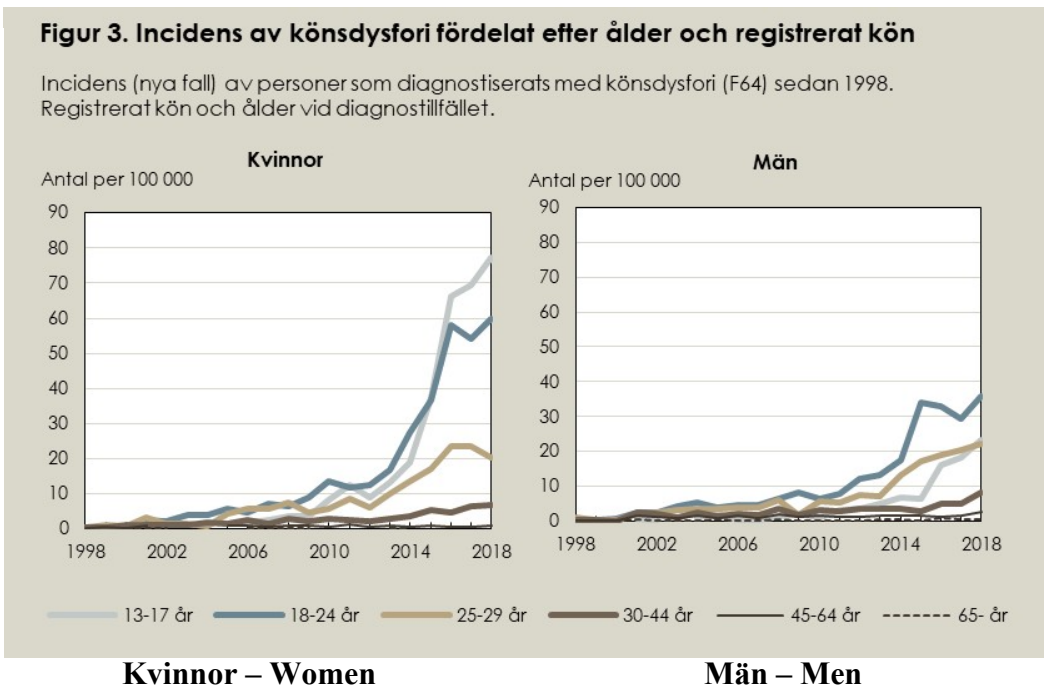
Kvinnor - Women Män – Men

Incidence

New cases of gender dysphoria have increased over the past five years. The increase has been greatest among children aged 13–17 (Figure 3), and especially among children aged 13–17 with registered as female at birth.

Figure 3. Incidence of Gender Dysphoria by Age and Registered Sex

Incidence (new cases) of people diagnosed with gender dysphoria (F64) since 1998. The sex and age are registered at the time of diagnosis.



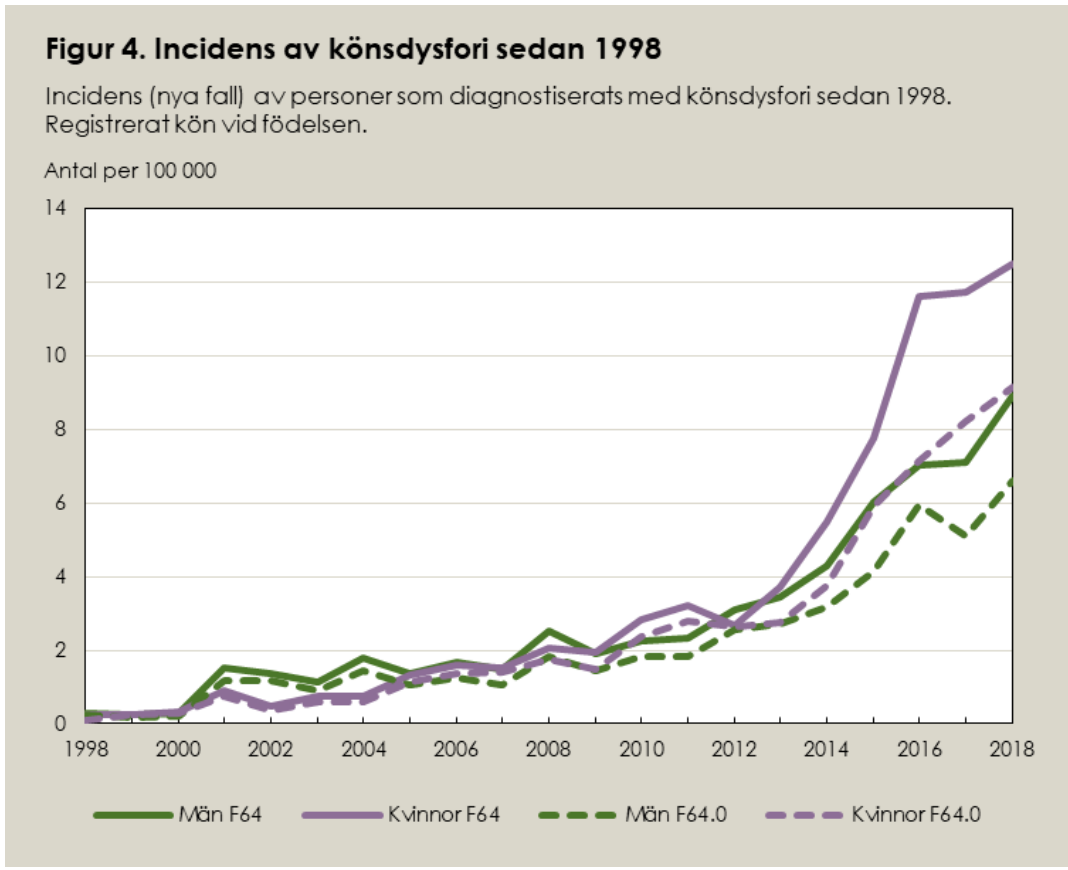
Cases per 100 000

Kvinnor – Women Män – Men

Figure 4 shows the incidence of new cases with any gender dysphoria diagnosis and new cases with a confirmed diagnosis. The figure indicates that for many cases under investigation today, the diagnosis of gender dysphoria is preliminary, and that the gap between the preliminary and confirmed diagnosis has increased over time. A possible explanation for the increased gap between the preliminary and the confirmed diagnoses could be that fewer people today receive a confirmed diagnosis as compared to prior years. However, the National Board of Health and Welfare' s analysis does not support this explanation.

Figure 4. Incidence of Gender Dysphoria since 1998

Incidence (new cases) of subjects diagnosed with gender dysphoria since 1998. Sex is that registered at birth.



Cases per 100 000

Män – Men **Kvinnor - Women**

Co-occurring Psychiatric Diagnoses

Table 1 shows co-occurring psychiatric diagnoses and self-harm behavior (including suicide attempts) among people with gender dysphoria in different age groups compared to the population for the period 2016 to 2018. The table shows that the prevalence of co-occurring psychiatric diagnoses is higher among persons with gender dysphoria than in persons who do not have gender dysphoria.

The prevalence of autism is very common among people with gender dysphoria relative to the population. Even less frequent diagnoses, such as bipolar or personality syndrome, are relatively common among people with gender dysphoria. Regarding self-harm behavior, including attempts at suicide, the incidence was also increased among people with gender dysphoria, especially among young people 18-24 and children 13-17 years of age and registered female at birth. Among people with gender dysphoria, depression and anxiety disorders are much more common among young people registered as female at birth than among young people registered as male at birth.

The National Board of Health has also conducted an analysis that takes into account the time before and after a preliminary gender dysphoria diagnosis. The National Board of Health can conclude that when other psychiatric diagnoses existed prior to a preliminary sex dysphoria diagnosis, there was an increased risk of attempted suicide or self-harm behavior during the ensuing investigation period. In addition, the National Board of Health can conclude that following a preliminary gender dysphoria diagnosis, a confirmed gender dysphoria diagnosis was associated with a lower risk of suicide or self-harm. However, the results cannot determine whether a confirmed diagnosis, or gender-affirming treatment for that matter, reduces the risk of suicide or self- harm behavior among people with gender dysphoria. It may be that the people in whom the diagnosis is confirmed after investigation are persons less likely to suffer from serious psychiatric problems.

Table 1. Prevalence of various psychiatric diagnoses (primary diagnosis in the open and inpatient care) among persons diagnosed with gender dysphoria (F64) and the population in 2016–2018, by age and registered sex.

Women (%)		**Age (years)**				
		13-17	**18-24**	**25-29**	**30-44**	**45-64**
With Gender Dysphoria	F1 Harmful use / dependence	1.5	4.4	4.3	2.6	2.9
	F2 schizophrenia etc.	0.4	1.0	1.4	1.1	4.3
	F30-31 Bipolar Disease	0.4	2.6	5.2	5.6	2.9
	F32-39 Depression	28.9	25.0	13.4	12.7	11.9
	F4 Anxiety disorders	32.4	28.5	23.3	19.8	13.3
	F60-61 Personality Syndrome	0.0	4.0	6.7	4.4	2.9
	F84 Autism	15.2	14.7	11.1	8.7	4.3
	F9 ADHD etc.	19.4	18.4	14.6	12.8	5.7
	X60-84, Y10-34 Self-harm	7.8	6.6	4.4	2.0	1.9
General Population	F1 Harmful use / dependence	0.7	1.8	1.2	0.9	0.9
	F2 schizophrenia etc.	0.0	0.2	0.3	0.4	0.7
	F30-31 Bipolar Disease	0.1	0.6	0.9	0.9	0.7
	F32-39 Depression	2.8	3.7	2.7	2.3	1.8
	F4 Anxiety disorders	4.2	6.4	4.9	4.4	3.2
	F60-61 Personality Syndrome	0.0	0.7	0.9	0.6	0.3
	F84 Autism	1.3	1.2	0.7	0.4	0.1
	F9 ADHD etc.	4.4	4.0	2.4	1.5	0.7
	X60-84, Y10-34 Self-harm	0.9	1.2	0.8	0.5	0.4

Men (%)	Age (years)	13-17	18-24	25-29	30-44	45-64
With Gender Dysphoria	F1 Harmful use / dependence	4.4	6.3	6.0	4.1	6.2
	F2 schizophrenia etc.	0.7	1.3	1.6	2.4	4.1
	F30-31 Bipolar Disease	0.0	1.3	2.7	2.8	2.8
	F32-39 Depression	13.8	18.2	19.2	14.9	10.0
	F4 Anxiety disorders	21.0	20.9	21.3	17.1	15.1
	F60-61 Personality Syndrome	1.5	3.6	3.5	3.7	3.9
	F84 Autism	12.3	16.3	12.7	9.4	4.4
	F9 ADHD etc.	13.0	13.5	10.2	8.8	6.2
	X60-84, Y10-34 Self-harm	4.4	4.6	2.3	2.3	1.3
General population	F1 Harmful use / dependence	0.8	2.3	2.1	1.8	1.8
	F2 schizophrenia etc.	0.1	0.4	0.6	0.7	0.8
	F30-31 Bipolar Disease	0.0	0.2	0.4	0.5	0.5
	F32-39 Depression	1.1	2.0	1.9	1.5	1.2
	F4 Anxiety disorders	1.7	3.0	2.9	2.5	1.8
	F60-61 Personality Syndrome	0.0	0.1	0.2	0.2	0.1
	F84 Autism	2.4	1.6	0.9	0.5	0.2
	F9 ADHD etc.	7.7	4.1	2.4	1.6	0.7
	X60-84, Y10-34 Self-harm	0.5	0.9	0.8	0.5	0.4

Suicide Mortality

Since 1998, a total of 6,334 persons have been diagnosed with gender dysphoria in Sweden. Of these, a total of 21 men and 18 women (registered sex at birth) have died from suicide. This represents 0.6 percent suicide mortality among persons with a gender dysphoria diagnosis since 1998.

To more closely analyze the risk of suicide among people with gender dysphoria, compared to the general population, the National Board of Health and Welfare has used standardized relative death rates from suicide (so-called SMR figures). SMR is calculated by comparing the observed number of suicides among people who have been diagnosed with gender dysphoria with the expected number of suicides in the general population.

An SMR number greater than 1 means that suicide is more common among people with gender dysphoria than it is in the population. The standardization is done by age and gender, over a ten-year period. As a comparison, SMR figures have also been calculated for people who have been cared for in inpatient or specialized outpatient settings for other types of psychiatric diagnoses.

Table 2 presents SMRs for gender dysphoria and various psychiatric diagnoses. It can be seen that gender dysphoric men and women (as registered at the time of diagnosis) had 4.9 and 13.7 times the risk of suicide, respectively, compared to the general population. As a comparison, people with other types of psychiatric diagnoses generally had even higher risks of suicide than people with gender dysphoria.

At the same time, people with gender dysphoria who committed suicide also had very high rates of serious psychiatric diagnoses, such as harmful use or addiction to various substances, schizophrenia or personality disorders (such as borderline personality disorder). As a result, it is difficult to interpret suicide risk among people with gender dysphoria - other co-occurring psychiatric diagnoses may be more pronounced contributing factors to suicide than the fact that a person has gender dysphoria.

Table 2. Suicide mortality within 10 years of diagnosis. Standardized death rates (SMR *) by registered sex and age at the time of diagnosis.

		SMR
Women	F1 Harmful use / dependence	18.4
	F2 schizophrenia etc.	17.7
	F30-31 Bipolar Disease	15.6
	F32-39 Depressions	11.0
	F60-61 Personality Syndrome	25.3
	F64 Gender dysphoria	13.7
	F84 Autism	10.9
Men	F1 Harmful use / dependence	10.3
	F2 schizophrenia etc.	13.9
	F30-31 Bipolar Disease	12.0
	F32-39 Depressions	10.6
	F60-61 Personality Syndrome	15.5
	F64 Gender dysphoria	4.9
	F84 Autism	5.6

* Indirect standardization with regard to gender, age (five-year classes) and person-years. Ten-year follow-up after diagnosis of persons 13-69 years at diagnosis.
Suicide risks (incl. Unclear cases, i.e., X60-84, Y10-34) for a ten-year period have been used to calculate the expected number of suicides in the different groups. The gender dysphoria group refers to the assigned gender.
The groups are not mutually exclusive i.e., the same person can be present in several groups

Summary Conclusions

The diagnosis of gender dysphoria is increasing in the population, especially among children and young adults, where the proportion of new cases among 13–17-year-old adolescents registered as female at birth has increased most. The increased rate of new cases will lead to an increasing total number of people diagnosed with gender dysphoria. In light of this, the development will require that health care is appropriately designed and sufficiently robust to ensure comprehensive investigation and treatment. In addition, treatment can be lifelong, which means that people with gender dysphoria need support from the healthcare system for extended time periods.

People with gender dysphoria, especially young people, have a high incidence of co-occurring psychiatric diagnoses, self-harm behaviors, and suicide attempts compared to the general population. Co-occurring psychiatric diagnoses among people with gender dysphoria are therefore a factor that needs to be considered more closely during investigation.

Suicide mortality rates are higher among people with gender dysphoria compared to the general population. At the same time, people with gender dysphoria who commit suicide have a very high rate of co-occurring serious psychiatric diagnoses, which in themselves sharply increase risks of suicide. Therefore, it is not possible to ascertain to what extent gender dysphoria alone contributes to suicide, since these psychiatric diagnoses often precede suicide.

Further clarification obtained by personal communication 14.may.2020.

1) many in the study population have a short follow-up period due to the sharp increase in recent years (see figures 3 and 4 in the report)

2) the analysis refers to a delimited group that received F64.9 first (ie preliminary gender dysphoria diagnosis, which according to practice should first be made, about 40% of the entire population), many in the population thus never had a preliminary diagnosis and were excluded from the analysis

3) this causes the problem of causality and selection to be greater than usual (and therefore our somewhat cautious interpretation of the results)

Model boundaries:

Persons who received F64.9 2009–2017 without having F64.0 before F64.9

Outcome of self-harm: care (or death) within closed or specialized outpatient care after the date of F64.9 with the following e-code: X60-84, Y10-34

Psychiatric diagnoses before investigation: (eg autism, ADHD, psychotic disorders)

Risk ratios (in this case hazard ratios, HR) are adjusted for gender and age at the first F64.9 diagnosis.

The National Board of Health has also conducted an analysis that takes into account the time before and after a preliminary gender dysphoria diagnosis. The authority can note that if other psychiatric diagnoses existed prior to a preliminary gender dysphoria diagnosis, there was an increased risk (HR = 1.92) of attempted suicide or self-harm behavior during the ensuing investigation period. Furthermore, the authority found that, following a preliminary gender dysphoria diagnosis, a finalized gender dysphoria diagnosis was associated with a lower risk (HR = 0.70) for suicide or self-harm behavior.

However, the results cannot determine whether an established diagnosis, or gender-affirming treatment for that matter (this was not studied but the interpretation would probably be the same as for diagnosis), reduces the risk of suicide or self-harm behavior among people with gender dysphoria - it may be that the individuals who are diagnosed with an established diagnosis after investigation are individuals who to a lesser extent have a serious psychiatric problem. "

Hope the answer can be helpful.

Best regards
Peter Salmi

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