

Psychosocial Outcomes of Fetal Alcohol Syndrome in Adulthood

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abstract

BACKGROUND AND OBJECTIVE: Primary disabilities in children prenatally exposed to alcohol have a major impact on their daily life. It is suggested that these issues persist into adulthood, but few studies have addressed the outcome in adults with prenatal exposure, especially those with fetal alcohol syndrome (FAS). The aim of this follow-up study was to investigate outcome variables, such as education, employment, health, and criminal acts, in 79 adults diagnosed with FAS.

METHODS: We carried out a national register-based study of 79 adults with an FAS diagnosis, at a mean age of 32. Education, social adjustment, and mental health outcomes were analyzed and compared with 3160 comparison individuals matched on age, gender, and place of birth.

RESULTS: The FAS group was much more likely to have received special education (25% vs 2%), be unemployed (51% vs 15%), and receive a disability pension (31% vs 3%) than the comparisons, but the levels of criminal offenses were similar. The FAS group had higher hospital admission rates for alcohol abuse (9% vs 2%) and psychiatric disorders (33% vs 5%) and was more likely to be prescribed psychotropic drugs (57% vs 27%).

CONCLUSIONS: Swedish children with FAS have quite diverse psychosocial outcomes in adulthood, considerably worse than for majority population peers. Potential risk and protective factors within the FAS group deserve study to enable development of effective interventions.

WHAT'S KNOWN ON THIS SUBJECT: Prenatal alcohol exposure can cause congenital neuropsychological and behavioral disabilities in later life. These usually lead to secondary disabilities (adverse outcome when the individual interacts with environmental settings), such as problems with school, the law, alcohol, or drugs.

WHAT THIS STUDY ADDS: This was a 30-year psychosocial register-based follow-up on adults with fetal alcohol syndrome and state care comparison group. The FAS-group had lower education and higher rates of unemployment, social welfare, and mental health problems than peers. Rates of criminality did not differ.

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Fetal alcohol syndrome (FAS) was first described more than 40 years ago.^{1,2} We now know that alcohol is a teratogen and that prenatal alcohol exposure can cause devastating alterations to the developing brain.³ The nondiagnostic umbrella term fetal alcohol spectrum disorders (FASDs) encompasses the range of possible adverse outcomes from alcohol exposure in utero, from neuropsychological and behavioral disabilities to full-blown FAS.⁴

Primary disabilities are congenital problems caused by the effect of teratogen on the developing brain and those that are normally observed in children with FASD are neuropsychological and behavioral impairments,⁵ which may last for life.⁶ Common neuropsychological impairments include reduced executive and cognitive functions⁷ and impaired verbal comprehension and perceptual reasoning⁸ and behavioral deficits, such as rule breaking and aggressiveness.⁹ Adolescents and adults with FASD also face secondary disabilities, such as problems at school, trouble with the law,¹⁰ alcohol abuse,¹¹ and mental illness.⁶ These disabilities may become adverse outcomes when the individual is interacting with environmental settings.¹² Despite the assumption that primary and secondary disabilities have a major impact on individuals with FASD, few studies have addressed long-term outcomes,^{11,13–16} especially reaching into adulthood.

The participants in this follow-up study consisted of 79 adults with a verified FAS diagnosis; some of them participated in previous studies^{17–25} on physical and psychosocial development. Based on these studies,^{17–25} and others,^{6,10,11,14,16} we expected that the FAS group would have experienced more problems in school, limited career options, mental illness, alcohol abuse, use of illicit drugs, and trouble with the law than majority population peers. Therefore,

this record-linkage study investigated possible secondary disabilities focused on outcome variables like these among the study cohort and compared them with a population matched by age, gender, and location. Many children with FAS are placed in state care²⁶ during their formative years. Therefore, we also have compared key outcome variables in adults with FAS with matched individuals from the comparison group who had been placed in care as children.

METHODS

This study was based on record-linkages between high-quality national registers,^{27,28} by using the unique 10-digit identification numbers given to all Swedish residents at birth or immigration. The Regional Ethical Review Board in Gothenburg approved the study, including the data linkage.

Study Populations

The FAS group was composed of individuals who all were diagnosed with FAS at the Children's Hospital in Gothenburg, Sweden, when they were infants or children and some of them participated in various studies.^{17–25} Together they constituted this study group consisting of 79 individuals (63% men) with an FAS diagnosis,^{1,29} which required (1) a documented history of alcohol abuse during pregnancy, (2) a characteristic pattern of facial anomalies, (3) growth retardation, and (4) neurodevelopmental abnormalities of the central nervous system.

The FAS group was followed up in national registers in 2011 when they had a mean age of 32 years (18–47 years) and compared with 3160 individuals who matched the FAS group on age, gender, and place of birth. The comparison group was constructed by Statistics Sweden by using the Total Population Register. In addition, a subgroup of 122 subjects from the comparison group, who had been placed in state care as children, was

constructed for further analyses of the psychosocial outcome variables.

Outcomes

The outcome variables were constructed with information from national registers. Most social outcomes were based on data from 2011, retrieved from the Total Population Register and the Longitudinal Integration Database for Health Insurance and Social Studies, both held by Statistics Sweden.³⁰ However, variables regarding criminality were created with information from the Register of Criminal Offenses, held by the National Council for Crime Prevention. This register is based on data from Swedish prosecutors and courts and contains information on Swedish court convictions of individuals aged ≥ 15 .

Three health registers held by the National Board of Health and Welfare were used to construct variables about mental health problems and deaths. Hospital admissions due to psychiatric disorders and self-inflicted injuries were identified in the National Patient Register (NPR) from 1968 onward. This register provides good coverage of the western region of Sweden from 1973 and comprehensive national coverage from 1987.³¹ The Prescribed Drug Register was used to identify psychotropic drugs prescribed outside hospitals from July 2005 to December 2011. The National Cause of Death Register, which covers all registered deaths in Sweden, including the date and the underlying and contributory causes of death, was used from 1968 onward. In both the NPR and National Cause of Death Register, the diagnoses and causes are coded according to the *International Classification of Diseases* (ICD) system. The NPR used the ICD-8 until 1986, the ICD-9 from 1987 and 1996, and the Swedish version of the ICD-10 from 1997.³²

The Child Welfare Intervention Register held by the National Board of Health and Welfare was used to

identify placements in state care from 1968 (foster family and residential care). Register information is mainly limited to dates and type, but not cause, of state care.

Statistical Analysis

SPSS 22 (IBM SPSS Statistics, IBM Corporation, Chicago, IL) was used for all statistical analyses. For categorical variables, the χ^2 test was used and when the overall χ^2 test was significant, standardized residuals (*R*) were used to determine what cells were major contributors to it. If $R > 2.0$, there was a contributor regarding the significant result. In a separate analysis, the FAS group was compared, using some key variables, with peers from the matched comparison group who had been placed in state care before age 18.

RESULTS

The FAS group consisted of 37% women and 63% men. Outcomes for men and women were similar (data not shown). Further analyses were therefore performed on the entire FAS group.

A large majority of the adults in the FAS group (81%) had been placed in state care as children, usually long-term care, compared with only 4% in the comparison group ($P < .001$). See Table 1 for further details.

Social Outcomes

Table 2 presents data on social outcomes. The FAS group differed from the comparison group in that 25% of them had attended special education ($P < .001$). For most of the subjects (59%) who were not in special education in primary school,

the highest completed education was secondary school. Far more individuals in the FAS group (82%) had a disposable income in the 3 lowest quintiles than in the comparison group (52%; $P < .001$). Men and women in the FAS group were less likely to have a biological child (32%) than peers in the comparison group (48%; $P < .001$). Crime conviction rates were 28% in the FAS group and 20% in the comparison group ($P = .100$); 6% in the FAS group had been convicted of severe crime, compared with 4% in the comparison group ($P = .305$).

Hospital Care, Deaths, and Psychotropic Drug Prescriptions

Table 3 presents data on health outcomes. A minority (9%) of the FAS group had been treated for alcohol-related disorder, which was a higher rate than in the comparison group (2%; $P < .001$). The figures for drug abuse were 6.0% and 2.5%, respectively ($P < .001$). A third of the FAS group (33%) had been treated for some kind of psychiatric disorder and 6% for a self-inflicted injury ($P < .001$). A majority in the FAS group (57%) had received at least 1 psychotropic drug between 2005 and 2011, compared with 27% in the comparison group ($P < .001$).

Extended Comparisons on Psychosocial Outcomes

A large majority (81%) in the FAS group had been placed in state care as children. Therefore, we conducted separate analyses comparing the FAS group with the 122 individuals from the comparison group who had been placed in care as children (Table 4).

Individuals in the FAS group were more likely to have attended special education (25%) than members of the comparison group who had been placed in state care as children (3%; $P < .001$). Crime conviction rates were lower (28%) in the FAS group than in the group of subjects from the comparison group who had been placed in state care as children (55%; $P < .001$). The rates of conviction for severe crime were particularly low in the FAS group (6%) compared with those from the comparison group who had been in state care (30%; $P < .001$, see Table 4).

DISCUSSION

The aim of this follow-up record-linkage study was to investigate possible secondary disabilities in adults with FAS, as measured by psychosocial outcomes. Follow-up studies on individuals with FAS reaching into adulthood are rare. This study group provided a good opportunity for doing a long-term follow-up, because it consisted of individuals with a verified FAS diagnosis. Generally, the results showed that the adults with FAS had a higher level of selected secondary disabilities than the comparison group, even though there were variations depending on measure of outcome. Thus, the results partly supported our hypothesis, that adults with FAS had experienced more problems at school, limited career options, and alcohol abuse and use of illicit drugs than the comparison group. On the other hand, they had experienced those problems to a lesser extent than subjects from the comparison group who had been placed in state care. In addition, the adults with FAS had experienced the same amount of trouble with the law as the comparison group, but fewer problems than comparison group members who had been in state care.

In general, the FAS group had poorer academic achievements than the comparison group. Streissguth and

TABLE 1 Characteristics of the FAS Group ($n = 79$) and the Comparison Group ($n = 3160$)

	FAS Group	Comparison Group
Placed in state care	81.0 (64)**	3.9 (122)
Time in state care		
Not placed	19.0 (15)	96.4 (3045)
Short-term, <5 y	20.3 (16)**	2.8 (87)
Long-term, >5 y	60.8 (48)**	0.9 (28)

Data are presented as percentages and numbers of individuals (in parentheses).

** $P < .001$. The FAS group differs significantly from the comparison group.

TABLE 2 Social Outcomes for the FAS Group ($n = 75$), Who Were Still Alive and Living in Sweden 2011, and the Comparison Group ($n = 2832$)

	FAS Group	Comparison Group
Highest completed education		
Special education	25.3 (19)**	1.6 (46)
Primary school, 9 y	26.7 (20)**	12.2 (343)
Secondary education	45.7 (32)	46.1 (1217)
Secondary education ^a	59.3 (32)	46.8 (1217)
Postsecondary education	4.9 (3)**	44.9 (1034)
Income and compensation		
Employed in November 2011	49.2 (30)**	85.3 (1967)
Disability pension	31.1 (19)**	3.2 (74)
Social welfare	27.9 (17)**	3.4 (79)
Educational allowance	0.0 (0)*	6.2 (144)
Disposable income		
First quintile	19.7 (12)	16.9 (389)
Second quintile	36.1 (22)**	17.0 (391)
Third quintile	26.2 (16)	18.4 (424)
Fourth quintile	13.1 (8)	22.1 (510)
Fifth quintile	4.9 (3)**	25.6 (591)
Family constellation		
Single parent with child	4.0 (3)	3.5 (98)
Cohabiting with child	16.0 (12)**	44.5 (1260)
Has biological child	31.6 (25)**	47.7 (1508)
Criminal acts and sanctions ^b		
Have record of court conviction	27.8 (22)	20.3 (641)
Have been convicted of severe crime	6.3 (5)	4.0 (127)

Data are presented as percentages and numbers of individuals (in parentheses).

^a For those >20 y alive and living in Sweden 2011, who were not in special education in primary school.

^b FAS group ($n = 79$) and the comparison group ($n = 3160$; not just those who were still alive and living in Sweden 2011).

* $P < .01$; ** $P < .001$. The FAS group differs significantly from the comparison group.

colleagues¹⁶ previously showed that a disrupted school experience was a common secondary disability for adults with FASD. The Swedish Education Act³³ makes it impossible to drop out of compulsory school, because the authorities are obliged to offer support and special education

for those who need it. In the current study, as many as 1 in 4 from the FAS group had attended special education. Interestingly, most of those in the FAS group who were not in special education in primary school still completed secondary education. Previous studies carried out on the

TABLE 3 Data for the FAS Group ($n = 79$) and the Comparison Group ($n = 3160$) Regarding Hospital Care, Deaths, and Psychotropic Drug Prescriptions

	FAS Group	Comparison Group
Hospital care by diagnosis at discharge		
Alcohol-related disorders or illicit drug abuse	12.7 (10)**	3.4 (109)
Illicit drug abuse	6.3 (5)*	2.5 (79)
Alcohol-related disorders	8.9 (7)**	1.6 (50)
Psychiatric disorder	32.9 (26)**	4.7 (147)
Age for psychiatric care, y		
0–17	19.0 (15)**	1.7 (53)
>18	13.9 (11)**	3.0 (94)
Self-inflicted injury/poisoning	6.3 (5)**	2.0 (62)
All-cause mortality	3.8 (3)	1.9 (60)
Any type of psychotropic drug prescription ^a	57.3 (43)**	26.5 (750)
Use of sleep/anxiolytics	45.3 (34)**	20.6 (583)
Use of neuroleptics	17.3 (13)**	3.0 (86)
Use of antidepressants	37.3 (28)**	17.9 (508)

Data are presented as percentages and numbers of individuals (in parentheses).

^a For those alive and living in Sweden 2011.

* $P < .01$; ** $P < .001$. The FAS group differs significantly from the comparison group.

FAS group up to the age of 13^{22,25,34} showed that, despite various interventions from society, primary disabilities persisted and had a negative impact on academic achievements.²⁵ The fairly positive figures on education in our study suggest that secondary disabilities are avoidable, and may be ameliorated by protective factors like special education and assistance in school.

In line with previous results, showing that as many as 8 to 9 of 10 individuals with FASD have no long-term employment or are unemployed in young adult age,³⁵ the FAS group in our study was more dependent on disability pensions and social welfare than the comparison group. Yet, it is noteworthy that almost every second person (49%) in the FAS group was employed and, therefore, also self-supporting. However, the figures on disposable income in the FAS group imply that they were employed mainly in lower-paid jobs, where income for some was supplemented by welfare benefits. According to the labor market regulations in Sweden,^{36,37} the Swedish Public Employment Service should provide special employment for individuals who need it and, importantly, all types of employment require routines and the ability to take responsibility, things that people learn at school. The fairly positive figures about employment may be because the highest completed education level for adults with FAS was relatively good.

In the FAS group, 13% (10 of 79) had received hospital care for alcohol problems or illicit drug use. Most of the FAS group had no court convictions and 6% (5 of 79) had been convicted of a serious crime. The rates of convicted crimes were similar to the comparison group, and contradict previous studies showing that it is common for adults with FASD to get into trouble with the law.³⁸ Noteworthy is that a previous

TABLE 4 Educational and Adult Outcomes of the FAS Group ($n = 79$) Compared With Those From the Comparison Group Who Had Been Placed in State Care as Children ($n = 122$)

	FAS Group	Placed in State Care Group
Special education ^a	25.3 (19)**	3.4 (4)
Highest completed education		
Secondary education ^b	45.7 (32)	51.4 (57)
Secondary education ^c	59.3 (32/54)	52.3 (57/109)
Income and compensation ^a		
Self-supporting	49.2 (30)	63.3 (62)
Hospital care by diagnosis at discharge		
Alcohol-related disorder or illicit drug abuse	12.7 (10)	25.4 (31)
Self-inflicted injury/poisoning	6.3 (5)	9.8 (12)
Psychiatric disorder	32.9 (26)	21.3 (26)
Any type of psychotropic drug prescription ^a	57.3 (43)	47.0 (55)
Have record of court conviction	27.8 (22)**	54.9 (67)
Have been convicted of a severe crime	6.3 (5)**	29.5 (36)

Data are presented as percentages and numbers of individuals (in parentheses).

^a For those alive and living in Sweden 2011.

^b For those >20 y alive and residents in Sweden 2011.

^c For those >20 y alive and residents in Sweden 2011 who were not in special education in primary school.

** $P < .001$. The FAS group differs significantly from the placed in state care group.

report¹⁶ showed that receiving a FAS diagnosis at a younger age may be a protective factor against development of secondary disabilities. In the current study, it should be emphasized that all subjects in the study group had full-blown FAS, whereas none of them had alcohol-related neurobehavioral problems. The fact that they all received an FAS diagnosis, and that they received it early in life, is probably important for the results. This factor, along with financial support and close contact with social workers during childhood,^{21,23,25} and the relatively positive educational attainment records in the FAS group, could possibly have contributed to the lower rates of marginalization. However, future studies are needed that focus on whether individuals with FAS are at increased risk of becoming victims of crime rather than committing them.

Previous studies have shown associations between prenatal alcohol exposure and an increased risk of suicide³⁹ and mental illness.^{6,40} In the current study 6% (5 of 79) in the FAS group had been treated in a hospital for suicide attempts and 1 (33%) in 3 for psychiatric disorders. Many in the FAS group also received psychotropic drug prescriptions,

such as sleeping medicine, anxiolytics, neuroleptics, and/or antidepressants. These findings suggest that mental health problems are common among adults who were diagnosed with FAS during childhood, far more so than in the comparison group. Previous reports show that children/youth with FASD tend to have problems getting along with their peers.⁴¹ This could be one of several reasons why many in our FAS group had been admitted to child/adolescent psychiatric care before the age of 18.

Children who have grown up in state care face a higher risk of poor academic performance in school, psychiatric problems, and criminality.⁴² Most individuals in the FAS group (61%) had actually grown up in long-term state care. Our data do not allow us to trace how experience of long-term state care has contributed to the results. However, research⁴³ on adopted children with FASD has shown that primary disabilities persist even if the environment improves, whereas the risk of developing secondary disabilities decreases for children with FASD when they are put in substitute family care on a long-term basis.⁴⁴ The results in this study were in line with these previous findings. Comparisons between our FAS group

and those from the comparison group who had been in state care, who had mostly been placed in short-term care at an older age, showed that criminality, measured by the court conviction variable, and medical care in the hospital because of alcohol or illicit drug abuse, were less common in the FAS group. Previous results have shown that an adequate FAS diagnosis could have a protective effect because it may give children benefit from appropriate services.⁴⁵ The FAS diagnosis may have contributed to improved out-of-home care, for instance through high-quality support/expertise provided to foster parents by physicians and nurses from health care, and from special education teachers, during the child's formative years. However, further studies are needed to focus on how state care works for children with FAS.

A shortcoming in this study is that we lack data that would enable us to study the influence of risk and protective factors for FAS children in a longitudinal perspective, a problem that also affects the comparison group. The quality of the data from registers used in this study is generally high, but a weakness is that the Child Welfare Intervention Register does not include data on reasons for placement in state care, and has no data on characteristics of services provided during time in care. Another weakness is the data on education. Missing values in the data on highest completed education are assumed to indicate special education. This assumption is based on data from the Swedish National Board of Education, which indicates that the frequency of special education in the Swedish general population closely matches the frequency of the missing values in the comparison group.

CONCLUSIONS

This study indicates that Swedish adults who were diagnosed with FAS

in childhood had diverse psychosocial outcomes as they got older, and that the problems probably are considerably worse than in the general Swedish population. The variation of outcomes in adulthood within the FAS group calls for further research into specific risk factors, for example cognitive disabilities. Such knowledge can be used to develop effective secondary prevention methods for children with problems associated with prenatal alcohol exposure.

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