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Social Conditions for People With Down Syndrome: A Register-Based Cohort Study in Denmark

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Abstract

Today, most persons with Down syndrome (DS) survive into middle age, but information on their social conditions as adults is limited. We addressed this knowledge gap using data from national registers in Denmark. We identified a national cohort of 1,998 persons with DS who were born between 1968 and 2007 (1,852 with standard trisomy 21, 80 with Robertsonian translocations and 66 with mosaicism) using the Danish Cytogenetic Register. We followed this cohort from 1980 to 2007. Information on social conditions (education, employment, source of income, marital status, etc.) was obtained by linkages to national registers, including the Integrated Database for Longitudinal Labor Market Research. For those aged 18 and older, more than 80% of persons with DS attended 10 years of primary school, with about 2% completing secondary or post-secondary education. About 4% obtained a full-time job, whereas the remaining mainly received public support from the government. Only a few (1–2%) of persons with DS were married or had a child. No significant differences in these social conditions were seen between males and females. More persons with mosaic DS attended secondary or post-secondary education, had a full-time job, were married, or had a child (18%, 28%, 15%, and 7%, respectively), compared with persons with standard DS (1%, 2%, 1%, and 1%, respectively). These data may provide families with better insight into social conditions and society with a better understanding of the social support needed for persons with DS.

Keywords

Down syndrome; mosaic trisomy 21; social conditions; offspring

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INTRODUCTION

In countries with well-developed health care systems, most people with Down syndrome (DS) now survive into adulthood, although DS mortality continues to be higher than that of the general population [Turner et al., 1990; Glasson et al., 2002; Yang et al., 2002; Zigman and Lott, 2007; Rasmussen et al., 2008; Schieve et al., 2009; McGrath et al., 2011; Tenenbaum et al., 2012]. The average life expectancy of persons born with DS in these countries including Denmark has increased substantially to almost 60 years [Penrose, 1949; Dupont et al., 1986; Baird and Sadovnick, 1989; Glasson et al., 2002; Yang et al., 2002; Zhu et al., 2013b]. Few previous studies have addressed social conditions, including education, employment, source of income, and marital status [Goldstein, 1988; Alderson, 2001; Carr, 2008; Bertoli et al., 2011]. Such information is important for families and society to better understand the support needed for persons with DS.

All children resident in Denmark are offered 10 years of compulsory education, usually from the age of 6 to 16 years, and education in public schools is free of charge to parents. Integration of children with disabilities into the Danish education system is a central principle [The Ministry of Children and Education, 2013]. Children with disabilities receive education integrated into classes with children without disabilities when possible, or in separate smaller classes, if needed. The Danish social welfare system also covers additional costs that parents may incur from caring for a child with DS [The Ministry of Social Affairs and Integration, 2012].

Adults with DS may be offered job training or part-time jobs supplemented by the municipality or disability pension [The Ministry of Social Affairs and Integration, 2012, 2013]. Municipalities also assist with housing in supported small groups. The Danish Down Syndrome Association (<http://www.downssyndrom.dk/>) and the Impartial Consultative Service for People with Disabilities (<http://www.dukh.dk/>) provide additional support and consultation.

Previous studies on social conditions have included small numbers of persons with DS [Goldstein, 1988; Alderson, 2001; Carr, 2008; Bertoli et al., 2011]. Using population-based data from several national registers in Denmark, we previously studied survival and hospitalization patterns among persons with DS [Zhu et al., 2013a,b]. In this study, we focus on social conditions among persons with DS, including education, employment, source of income, and marital status, comparing males and females as well as persons with different DS karyotypes.

METHODS

Study Design and Study Population

We identified a nationwide cohort of 3,530 persons with DS from the Danish Cytogenetic Register by December 2007, which has been described elsewhere [Zhu et al., 2013b]. The Danish Cytogenetic Register, founded in 1968, is based on reports from cytogenetic laboratories throughout the country and provides virtually complete coverage of constitutional chromosomal abnormalities diagnosed in Denmark [Nielsen, 1980]. A

karyotype based on studies of peripheral blood is available for all cases. We linked the cohort to a number of national registers, including the Civil Registration System, the Register of Causes of Death, the National Hospital Register, the Medical Birth Register, and the Integrated Database for Longitudinal Labor Market Research (IDA). In this study, we excluded 1,266 persons who were born before April 1, 1968, 193 persons who did not survive to January 1, 1981, and 73 persons (66 died before age of 1) who had no data on social conditions. The final cohort consisted of 1,998 individuals.

All data linkages were based upon the personal civil registration number (CPR number), which was introduced with the establishment of the Civil Registration System [Pedersen, 2011] in Denmark in April 1968 and is assigned to each resident. The personal number, which includes date of birth and a code for sex, is unique to each resident, allowing complete follow-up and linkage to all national civil registers. It is generally accepted that these national registers have a virtually complete coverage of the entire population of Denmark [Pedersen, 2011]. This study was approved by the Danish Data Protection Agency.

Data on Social Conditions

Information on social conditions was obtained from the IDA [Statistics Denmark, 2012], established in 1980, which contains information on education, employment, income, and marital status and is updated annually. Education is defined as the highest education a person completed as of October 1 in a given calendar year. Any child resident in Denmark is subject to 10 years of compulsory education usually from the age of 6 to 16 years, including the pre-school year and the 1st–9th school years. Many children also attend the voluntary 10th school year before entering the secondary school system. The pre-school year, the 1st–9th school years, and the 10th school year, constitute the primary school education. We grouped education into four categories: <9th school year, 9th school year, 10th school year, and >10th school year. Information was also available on employment status and on income. Gross income is the sum of all earnings in a given calendar year, including salary, student stipends (given to all students from the government), public support from the government and other earnings, and is adjusted for the consumer price index (CPI) in Denmark from 1980 to 2007 to make income comparable from year to year. The CPI for 2007 was set as 100. We set the exchange rate as 5.5 Danish Drone (DKK) to 1.0 US dollar (USD). Marital status was categorized as unmarried and married. If marital status changed during the follow-up the date of this event was also available.

Data on Children and Spouses

Information on children and spouses was obtained from the Medical Birth Register and the Civil Registration System up to 2008. These data were based on legal reports, and no information on results of paternity testing was available. We examined if spouses or children had a diagnosis of DS by linkage to both our DS cohort and the National Hospital Register.

Statistical Analysis

We presented the overall distribution of education, employment, income, and marital status, as well as having a child, for all persons with DS who were 18 years or older during the period from 1980 to 2007 (from 1980 to 2008 for having a child). We also examined

whether social conditions differed between males and females, and among different karyotypes by using χ^2 test, age standardization (education), logistic regression (employment, marriage, and having a child), and one-way ANOVA test or linear regression (income). In the regression models we also included age group (18–25 years and 26–39 years) as a covariate.

RESULTS

Basic Characteristics

Table I provides distribution of sex and karyotype of the 1,998 persons with DS by age groups. By the end of follow-up period, more persons with mosaic DS were in the age group of 18–25 years.

Education

For persons who were 18 years or older at the end of follow-up, more than 80% finished 10 years primary school (including those who attended the 9th school year, the 10th school year, and beyond), and about 2% had a secondary or post-secondary education, including high school (n=4), vocational education (n=12), or higher education (n=4). No difference in education was seen between males and females, whereas more persons with mosaic DS obtained an education beyond primary school than persons with other karyotypes. There was no difference in attending higher education between the two time points of 1997 and 2007, but fewer children attended the 10th year after finishing the 9th year in 2007 (Table II).

Employment

A total of 34 (4%) persons with DS aged 18 and older had a job as their main income source for some time during follow-up, and the rest received a disability pension. Persons with mosaic DS had a job more often than persons with other karyotypes (28% vs. 3%) (Table III).

Income

Mean yearly gross income for persons with DS aged 18 or older was 138,000 (\pm SD 52,000) DKK, or 25,000 (\pm SD 9,500) USD. Income increased with age, and there was no difference in income between males and females (Table IV). Income was higher for persons with Robertsonian translocation DS and lower for persons with mosaic DS, but after adjustment for age, the difference for persons with mosaic DS was reduced and no longer statistically significant.

Marital Status

A total of 14 persons (1.5%) with DS married during the study period, and mean age at marriage was 28.4 years (range 23.7–33.5 years). None of them experienced divorce during the study period. There was no difference in marital status between males and females, while persons with mosaic DS were more often married than persons with other karyotypes (15% vs. 1%) (Table V).

Having a Child

By the end of 2008, a total of 13 persons with DS had at least one child; 11 children (including a pair of twins) were born to 7 women with DS (2 women with mosaic DS), and 8 children were reportedly fathered by 6 men with DS (1 with mosaic DS). None of these 19 children were diagnosed with DS. In none of the cases did the other parent have DS. No difference in having a child was observed between females and males with DS, whereas persons with mosaic DS had a child more often than persons with other karyotypes (7% for mosaic DS vs. 1% for standard trisomy 21 and 2% for Robertsonian translocation DS). Mean ages at delivery were 30.5 years (range 27–37 years) for mothers with DS and 27.9 years (range 25–30 years) for fathers with DS.

DISCUSSION

In this national cohort of persons with DS who were born between 1968 and 2007 and followed from 1980 to 2007, we found that more than 80% attended 10 years of primary school by the age of 18, with about 2% completing a secondary or post-secondary education. About 4% of people with DS older than 18 years of age had a fulltime job for some time during follow-up, and for the rest, their income was mainly based on public support from the government. A few (1–2%) of persons with DS were married or had a child. Persons with mosaic DS more often achieved a higher education, had a full-time job, got married, and had a child.

A cross-sectional survey among 518 persons with DS in Rome, Italy reported that 100% of children with DS were enrolled in the public school system and that about 10% of adults were working with a regular contract (including in a sheltered workshop) [Bertoli et al., 2011]. An older Danish study examining the living conditions of 38 adults with DS (age 40–50 years) in Aarhus county reported that 23 persons (61%) had worked in sheltered workshops during 1984 [Goldstein, 1988]. A longitudinal study of 54 persons with DS in London, UK reported that at ages 30–35, 3% had a full-time job, and 6–9% had part-time employment [Carr, 2008]. We found that 4% of persons with DS aged 18 and older ever had a full-time job, but we did not have information on part-time jobs or work in sheltered workshops. In 2007, the average gross income for the general population aged 15 and older was about 270,000 DKK (about 49,000 USD) in Denmark [Statistics Denmark, 2009], and persons with DS with a reported income had about half of the average income.

We were able to identify several pregnancies and children born to mothers with DS in the medical literature, with 10 out of 28 children having DS [Bovicelli et al., 1982; Shobha et al., 1990]. Reports of males with DS fathering children are fewer; we identified reports of three children and one pregnancy loss [Sheridan et al., 1989; Bobrow et al., 1992; Zuhlke et al., 1994; Pradhan et al., 2006]. All three children (two boys and one girl) were born without DS. In these cases, paternity was verified by several genetic markers. The reported maternal or paternal karyotype was standard trisomy 21 (47,XX,+21; 47,XY,+21) in these case reports. To our knowledge, our study is the first population-based study, and we found 19 children born to persons with DS in our cohort. These children were born to persons with various maternal or paternal karyotypes except for paternal Robertsonian translocation. However, we are unable to rule out non-paternity in the eight children born to six fathers

with DS. Our finding that none of the children born to parents with DS had DS was not entirely unexpected; it is hypothesized that euploid gametes may have a selective advantage over aneuploid gametes [Ekelund et al., 2008]. In addition, some of the families may have utilized prenatal screening.

Survival is reported to be better for persons with mosaic DS than persons with other karyotypes [Shin et al., 2010; Zhu et al., 2013b]. Some studies also suggest that children with mosaic trisomy 21 appear to have better intellectual development than those with standard trisomy 21 [Rosecrans, 1968; Fishler et al., 1976]. Consistent with these findings, we found that persons with mosaic DS more often achieved a higher education, had a full-time job, got married, and had a child.

A strength of the present study is that we identified persons with DS from the Danish Cytogenetic Register, allowing classification into different karyotypes based on the results of cytogenetic testing. These persons were followed for nearly 30 years and we had virtually complete sampling and follow-up due to the high quality Danish population-based registers. On the other hand, we had no information on social life, part-time employment, or social networks. To get a more complete picture of the social conditions in adulthood for people with DS, future studies should include more details on social, work, and family life, including where and with whom they live, and on daily activities, including information on part-time employment and social life.

Our data show that the large majority of people with DS in Denmark during the years from 1980 to 2007 attend primary school and receive government benefits. Some, especially those with mosaic DS, are employed and earn an income. The Danish DS Association and other relevant organizations may advocate for and support persons with DS in their efforts toward gaining employment.

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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TABLE I
 Age Distribution by the End of Follow-up According to Sex and Karyotype among Persons with Down Syndrome (Birth Year: 1968–2007; Follow-up: 1980–2007)

	0–6 years		7–17 years		18–25 years		26–39 years		Total	
	n	%	n	%	n	%	n	%	n	%
Total	426	21.3	628	31.4	352	17.6	592	29.6	1,998	100.0
Sex										
Female	203	47.7	275	43.8	147	41.8	268	45.3	893	44.7
Male	223	52.3	353	56.2	205	58.2	324	54.7	1,105	55.3
Karyotype										
Standard trisomy 21	405	95.1	589	93.8	318	90.3	540	91.2	1,852	92.7
Robertsonian translocation DS	13	3.1	21	3.3	13	3.7	33	5.6	80	4.0
Mosaic DS	8	1.9	18	2.9	21	6.0	19	3.2	66	3.3

DS: Down syndrome.

χ^2 tests: $P = 0.39$ for sex, and $P = 0.011$ for karyotype.

Highest Completed Education by Age Group, Sex, Karyotype, and Calendar Year among Persons with Down Syndrome

TABLE II

	<9th school year			9th school year			10th school year			>10th school year		
	n	%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI
Age group, years ^a												
0-6	1,695	100.0		0	0.0		0	0.0		0	0.0	
7-17	789	50.3	(44.0-56.6)	470	29.9	(25.9-33.9)	310	19.7	(16.7-22.7)	1	0.1	
18-25	141	15.0	(11.0-19.0)	120	12.7	(9.7-15.7)	662	70.2	(67.2-73.2)	20	2.1	
26-39	74	12.5	(8.5-16.5)	68	11.5	(7.5-15.5)	431	72.8	(69.8-75.8)	19	3.2	
Sex ^b												
Female	58	14.0	(9.0-19.0)	46	11.1	(6.1-16.1)	300	72.3	(68.3-76.3)	11	2.7	(1.7-3.7)
Male	84	15.9	(11.9-19.9)	74	14.0	(10.0-18.0)	362	68.4	(64.4-72.4)	9	1.7	(0.7-2.7)
Karyotype ^b												
Standard trisomy 21	133	15.5	(11.5-19.5)	108	12.6	(8.6-16.6)	606	70.6	(66.6-74.6)	11	1.3	(0.3-2.3)
Robertsonian translocation DS	8	17.4	(7.4-27.4)	6	13.0	(3.0-23.0)	30	65.2	(51.2-79.2)	2	4.3	(1.3-7.3)
Mosaic DS	1	2.5	(0.5-4.5)	6	15.0	(5.0-25.0)	26	65.0	(51.0-79.0)	7	17.5	(7.5-27.5)
Calendar year ^b												
1997	67	12.3	(7.3-17.3)	55	10.1	(5.1-15.1)	411	75.6	(71.6-79.6)	11	2.0	(1.0-3.0)
2007	136	15.1	(11.1-19.1)	115	12.7	(8.7-16.7)	632	70.0	(66.0-74.0)	20	2.2	(1.2-3.2)

Numbers in parentheses are age-standardized rates with 95% confidence intervals. DS, Down syndrome.

^a A person is counted in every relevant age category during follow-up.

^b Among persons aged 18+ years at the end of follow-up.

TABLE III

Employment among Persons with Down Syndrome Aged 18+ by Sex and Karyotype

	N	n (%) of persons employed	Crude OR	Adjusted OR ^a (95% CI)
Total	944	34 (3.6)		
Sex				
Female	415	18 (4.3)	1.0	Reference
Male	529	16 (3.0)	0.7	0.7 (0.4–1.4)
Karyotype				
Standard trisomy 21	858	21 (2.4)	1.0	Reference
Robertsonian translocation DS	46	2 (4.3)	1.8	1.6 (0.4–7.2)
Mosaic DS	40	11 (27.5)	15.1	24.8 (9.8–62.7)

Logistic regression. CI, confidence interval; DS, Down syndrome; OR, odds ratio.

^aAdjusted for age group.

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TABLE IV

Mean Yearly Income (Crude Income)^a (/10,000 USD) among Persons with Down Syndrome Aged 18+ by Age Group, Sex, and Karyotype

	Mean	SD	Difference in means ^b	(95% CI)
Overall	2.50	0.95		
Age group, years				
18–25	2.18	1.06	Reference	
26–39	2.93	0.55	0.74	(0.69 to 0.80)
Sex				
Female	2.49	0.91	Reference	
Male	2.51	0.99	0.03	(–0.04 to 0.10)
Karyotype				
Standard trisomy 21	2.50	0.95	Reference	
Robertsonian translocation DS	2.61	0.75	0.12	(0.02 to 0.21)
Mosaic DS	2.34	1.35	–0.12	(–0.47 to 0.23)

Linear regression. CI: confidence interval, DS: Down syndrome, SD: standard deviation.

^a Adjusted for the consumer price index (CPI) and the CPI for 2007=100. The exchange rate was set as 5.5 Danish Drone (DKK) to 1.0 US dollar (USD).

^b Adjusted for age group, except for the category of age group.

TABLE V

Marriage among Persons with Down Syndrome Aged 18+ by Sex and Karyotype

	N	n (%) of persons married	Crude OR	Adjusted OR ^a (95% CI)
Total	944	14 (1.5)		
Sex				
Female	415	9 (2.2)	1.0	Reference
Male	529	5 (0.9)	0.4	0.4 (0.1–1.3)
Karyotype				
Standard trisomy 21	858	8 (0.9)	1.0	Reference
Robertsonian translocation DS	46	0 (0.0)	—	—
Mosaic DS	40	6 (15.0)	18.8	27.4 (8.5–88.9)

Logistic regression. CI, confidence interval; DS, Down syndrome; OR, odds ratio.

^aAdjusted for age group.