

Down syndrome in Israel

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Abstract — The incidence of Down syndrome was studied in Jerusalem for the years 1964-1970 showing an overall incidence rate of 2.43 per 1,000 live births. A National Down Syndrome Register was established in 1978 and data on annual incidence and mortality rates from 1979-1997 is presented. The incidence in 1997 was 1.0 per 1,000 live births, but 2.32 per 1,000, when live births and terminated pregnancies are summed. Infant mortality has generally decreased in the past 20 years in Israel, and a decrease in infant mortality in Down syndrome has also been noted. This is due to better medical treatment and increased parental involvement in the care for infants with Down syndrome.

Keywords — National Down Syndrome Register, incidence rates, infant mortality, Israel

Introduction

There has been a decline in infant mortality in Israel over the last 25 years. In 1997 the infant mortality rate for Jews was 4.9 per 1,000 live births, whereas for Arabs it was 9.3 resulting in a total rate of 6.2 (Ifrah, 1999).

This decline affects Jews as well as Arabs, with an especially marked decline in mortality due to infectious causes.

Congenital malformation continues to be the commonest cause of infant mortality although there has been a 61% decrease among Jews (and 38% decrease among Arabs) in mortality from this cause since 1970. Contributing causes for the difference between Jews and Arabs could be due to the higher extent of consanguineous marriage in the Arab population and a lower utilisation of prenatal screening.

Prenatal screening

Screening tests for carriers of the Tay-Sachs gene started in 1974, and in 1978 a national program for the prevention of births defects was implemented by the Ministry of Health. Since 1979 data has been collected and analyzed on the births of infants with Down syndrome. The Down Syndrome National Register receives information from routine notifications from delivery rooms, cytogenetic laboratories in all hospitals and annual reports from hospital nurseries.

In 1978 free amniocentesis was offered to women over the age of 37 years, but since 1993 the age limit has been

reduced to 35 years. The use of amniocentesis was 61% in pregnant Jewish women (over 35 years) in 1997 and 14% in younger women with a total 22.2% of all pregnant Jewish women. For Arab women the total utilisation was 4.2% (Ifrah, 1999). The use of amniocentesis in the target group of women over 35 years is higher than in other countries (England, the United States, Holland, Australia), where Steele and Stratford (1995) found no more than 50% utilization.

In 1990, 53% of the cases of Down syndrome among Jewish women were detected and terminated during pregnancy, whereas in 1997 this percentage had increased to 61.2%. In the Arab population 8% of pregnancies with Down syndrome were terminated in 1991, whereas in 1997 that figure had increased to 35.7% (Ifrah, 1999).

In 1997, there were 86,140 births among Jewish women and 38,338 amongst Arab women with the number of amniocenteses performed being 19,135 and 1,607 for Jewish and Arab women respectively. The total number of cases of Down syndrome diagnosed antenatally was 219 cases among Jewish women and 70 among Arab women. There were 85 live births among Jewish women and 45 live births among Arab women and 134 terminations among Jewish women and 25 terminations among Arab women during this period (Ifrah, 1999).

Trends in the incidence of Down syndrome

A prospective study from Jerusalem (Harlap, 1973) followed about 42,000 deliveries and found 103 infants with Down syndrome between the years 1964-1970. The incidence rates according to maternal age can be seen in Table 1. The overall incidence rate for the period was 2.43 per 1,000 births with a tendency to increasing incidence with increase in maternal age. This rate is higher than some other countries during the same period, e.g. Australia (1.19), England (1.39) and the United States (1.44) (Steele, 1996).

The Ministry of Health in Israel started a National Program for Detection and Prevention of Birth Defects in 1974 and has collected data on Down syndrome since 1979. The number of live births and the incidence rate for Jews and non-Jews is shown in Table 2 (Klein *et al.*, 1998). The total or true incidence rate for Down syndrome in 1997, including both live births and terminated pregnancies, for Jews and non-Jews was 2.32 per 1,000. This rate is not appreciably different from the rate found for the years 1964-1970 (Harlap, 1973), namely 2.43.

Trends in mortality

About 85% of deaths due to congenital malformations occur during the first year and a further 10% during the second to fourth years of the child's life. In 1995 the mortality rates in the 0-4 age group were 39.7 per 100,000 for Jewish males, 27.4 for Jewish females and, 89.2 for

Maternal age bands in years							Total rate
15-19	20-24	25-29	30-34	35-39	40-44	> 45	
1.08	0.73	1.50	2.17	5.79	17.95	15.08	2.43

Table 1. Incidence rates (per 1,000 births) of Down syndrome in Jerusalem 1964-1970.

males and 80.9 for females in the Arab population. Mortality due to congenital malformations declined in the years 1970-1995 by 70% for Jewish males, 76% for Jewish females and 47% for Arab males and 46% for Arab females (Ifrah, 1999).

Infant mortality (deaths until the end of the first year) for children with Down syndrome is shown in Table 3 and mortality up to the age of 14 years is shown in Table 4 (Klein *et al.*, 1998).

These figures demonstrate a clear decrease in mortality since 1979. This decrease is caused by several factors. Firstly, because of technical developments in medicine, such as improved surgical techniques for cardiac and gastrointestinal malformations. Secondly, earlier and more effective medical treatment of infections and thirdly, a change in attitude both by parents, and also by medical and nursing staff in hospitals towards a much more positive attitude towards children born with Down syndrome (Sadetzki *et al.*, 1999a, Sadetzki *et al.*, 1999b).

Year	Total number of live births with Down syndrome	Rate per 1,000 live births for Jews	Rate per 1,000 live births for non-Jews
1979	109	1.1	1.5
1980	107	1.0	1.4
1981	111	1.1	1.5
1982	128	1.3	1.5
1983	125	1.3	1.2
1984	120	1.2	1.3
1985	131	1.3	1.4
1986	131	1.3	1.3
1987	130	1.5	0.9
1988	123	1.3	0.9
1989	116	1.1	1.2
1990	103	1.0	1.1
1991	97	1.0	0.8
1992	115	0.7	1.8
1993	114	0.9	1.3
1994	96	0.7	1.2
1995	107	0.8	1.2
1996	105	0.9	0.9
1997	130	1.0	1.2

Table 2. Total number of live birth persons with Down syndrome and incidence rates for Jews and non-Jews in Israel 1979-1997.

Year	Number of deaths	Percentage of total
1979	50	45.9
1980	52	48.6
1981	35	31.5
1982	41	32.0
1983	34	27.2
1984	33	27.5
1985	23	17.6
1986	25	19.1
1987	22	16.9
1988	23	18.7
1989	24	20.7
1990	14	13.6
1991	13	13.4
1992	22	19.1
1993	22	19.3
1994	10	10.4
1995	11	10.3
1996	9	8.6

Table 3. Infant mortality (until year one) for children with Down syndrome in Israel 1979-1996.

Year	Number of deaths	Percentage of total
1979	63	57.8
1980	64	59.8
1981	44	39.6
1982	54	42.2
1983	43	34.4
1984	41	34.2
1985	39	29.8
1986	40	30.5
1987	33	25.4
1988	35	28.5
1989	36	31.0
1990	27	26.2
1991	21	21.6
1992	32	27.8
1993	28	24.6
1994	14	14.6
1995	13	12.1
1996	11	10.5

Table 4. Mortality of children with Down syndrome until age 14 in Israel 1979-1996.

Conclusion

The total incidence of Down syndrome during the years 1964 through 1970 was found to be 2.43 per 1,000 live births. Data from the National Down Syndrome Register for the years 1979 through 1997 showed a decline in the incidence, but when live births and terminated pregnancies were summed the true incidence rate in 1997 was 2.32. Mortality rates have shown a clear decline since 1979 due to medical advances, but also due to a much more positive public attitude towards persons with Down syndrome in Israeli society.

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