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Spina bifida and anencephaly in Scotland

VERA CARSTAIRS, SUSAN COLE

Abstract

Data obtained from routine sources showed that from 1971 to 1982 the birth prevalences of spina bifida and anencephaly in Scotland fell. When known terminations after routine α fetoprotein screening were added to total births the adjusted birth prevalence could be calculated. In 1974-82 this fell by 40% for spina bifida (3·0-1·8) and 36% for anencephaly (2·2-1·4). These findings were compared with data on birth prevalences in England and Wales, Northern Ireland, and Glasgow.

The fall in birth prevalences of spina bifida and anencephaly over the past decade appears to have been due both to a true fall in incidence as well as to increased screening and termination for these conditions.

Introduction

From 1971 to 1982 the birth prevalence—the number of affected infants, born dead or alive, expressed as a proportion of all live births and stillbirths—of spina bifida and anencephaly fell substantially in Scotland. This coincided with the introduction of a widespread antenatal α fetoprotein screening programme. It was not clear whether the observed fall was wholly related to screening and termination of affected pregnancies or whether a true fall in incidence had occurred as well.

The use of the Scottish neonatal discharge record (form SMR11) in providing information on the incidence of congenital malformations has been discussed previously.[1] In the present study we extended the examination to other routine records and included information from the screening laboratories on termination of affected pregnancies. We thus examined trends in the birth prevalence of spina bifida and anencephaly in Scotland.

Information Services Division, Common Services Agency, Scottish Health Service, Trinity Park House, Edinburgh EH5 3SQ
VERA CARSTAIRS, BSC, assistant director
SUSAN COLE, MD, FRCOG, community medicine specialist

Correspondence to: Mrs V Carstairs.

Methods

Spina bifida—By searching Scottish neonatal discharge records (SMR11s) we obtained the number of liveborn infants with spina bifida. Supplementary information was obtained by searching general hospital discharge summaries (SMR1s), from which episodes of care in paediatric or other units could be gathered. The records allowed patients to be identified and repeat episodes of hospital care to be excluded. The Scottish neonatal discharge record was not introduced until 1970 and had achieved 75% national coverage of liveborn infants by 1980, but SMR1 records were complete for the whole study period. The two sources of data were cross checked against identifiable information on deaths from the General Register Office (Scotland); this source showed the few cases not treated in hospital. We included in our findings all cases of spina bifida with or without hydrocephaly (International Classification of Diseases 741.0, 741.9) recorded as either a main or a secondary cause. The above sources were believed to provide a fairly accurate count of liveborn infants with spina bifida as it was assumed that all infants with spina bifida would receive hospital treatment at some time unless they were expected to die within a short period. The total birth prevalence (the number of affected infants, born dead or alive, per 1000 live births and stillbirths) was achieved by adding the number of stillbirths with spina bifida each year. Data on deaths of babies with spina bifida also allowed us to estimate numbers of survivors.

Anencephaly—Numbers of stillbirths and deaths in babies with anencephaly were abstracted from the annual reports of the Registrar General for Scotland.

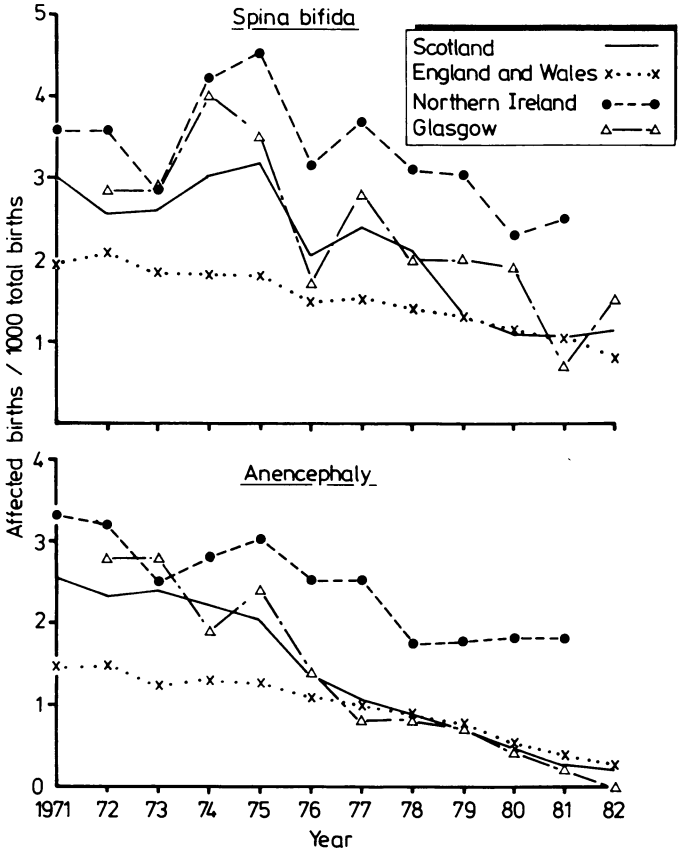
In addition, data on total births with and total cases of both conditions were provided by Greater Glasgow Health Board, which is one of the centres for the European Collaborative Study (F Hamilton, personal communication).

Results

Table I shows the birth prevalences of spina bifida and anencephaly in Scotland. Between 1971 and 1982 the birth prevalence of spina bifida fell from 3·0 to 1·1/1000 total births and that of anencephaly from 2·6 to 0·2/1000. The figure shows the comparable birth prevalences for 1971-82 of spina bifida (top) and anencephaly (bottom) (obtained from published studies that used different methods of data collection) for Glasgow (F Hamilton, personal communication), England and Wales,[2] and Northern Ireland.[3 4] The birth prevalence of spina bifida appeared to have fallen in all areas. In 1971 the prevalence in Scotland greatly exceeded that in England and Wales, but current prevalences are similar for both countries. The prevalence in Northern Ireland exceeded that in Scotland in all years. The prevalence in

TABLE I—*Known number of children born with spina bifida and anencephaly, Scotland 1971-82*

	1971	1972	1973	1974	1975	1976	1977	1978	1979	1980	1981	1982
Total births	87 883	79 603	75 265	70 943	68 708	65 524	62 895	64 819	68 841	69 355	69 490	66 582
Spina bifida:												
Hospital records	206	157	151	165	169	108	119	116	77	60	63	64
Death registrations only	30	19	18	27	25	11	16	5	4	3	4	3
Live births	236	176	169	192	194	119	135	121	81	63	67	67
Stillbirths	29	27	26	22	24	20	16	15	10	12	6	8
Total affected births	265	203	195	214	218	139	151	136	91	75	73	75
Incidence/1000 total births	3·0	2·6	2·6	3·0	3·2	2·0	2·4	2·1	1·3	1·1	1·1	1·1
Anencephaly:												
Stillbirths	204	170	165	145	132	77	57	48	40	27	17	11
Deaths	20	15	16	11	8	12	9	9	7	5	2	4
Total affected births	224	185	181	156	140	89	66	57	47	32	19	13
Incidence/1000 total births	2·6	2·3	2·4	2·2	2·0	1·4	1·1	0·9	0·7	0·5	0·3	0·2



Total number of babies born with spina bifida (top) or with anencephaly (bottom) as a proportion of total births, in Scotland, Glasgow, England and Wales,[2] and Northern Ireland,[3 4] 1971-82.

Glasgow also exceeded that in Scotland in 1972-5; the trend was not consistent, and the dramatic reduction in 1981 was not sustained in 1982. An interesting drop in the prevalence in all countries occurred in 1976, for which we have no explanation.

Birth prevalences of anencephaly also were higher in Scotland than in England and Wales over the early part of the series but very similar after 1977. The prevalence remained high in Northern Ireland but, as with spina bifida, fell after a peak in 1975. The prevalence in Glasgow was higher than that in the whole of Scotland in 1972-3, but was similar after 1976.

Additional data for both Scotland and the Greater Glasgow Health Board area indicated not only a fall in prevalence of both conditions among total births but also a fall in the "adjusted" birth prevalence when total births were combined with terminations (table II). We have assumed that the figures in table II represent the number of live births and stillbirths with spina bifida and anencephaly that would have occurred if there had been no screening programmes; this thus provides an adjusted birth prevalence.

We did not know how many fetuses in pregnancies terminated for other reasons had had anencephaly or spina bifida and therefore omitted these other terminations from both numerator and denominator. As the Abortion Act was in operation throughout the series and the numbers of abortions did not vary greatly from year to year after 1974, the number of unrecognised cases in this group was probably fairly constant. Clearly, a true incidence of anencephaly or spina bifida, reflecting the incidence of the abnormality in all conceptions, cannot be determined.

The above data indicate that from 1974 to 1982 the adjusted prevalence of spina bifida fell by 40% whereas the birth prevalence fell by 63%; the falls in prevalences of anencephaly were 36% and 91% respectively. Data for Glasgow were less consistent but mirrored the same trend. Data recently reported from the west of Scotland showed a fall in the combined adjusted birth prevalence for spina bifida and anencephaly from 5·1/1000 total births in 1976 to 4·0 in 1981 compared with from 3·9 to 3·5 in Scotland and from 4·3 to 4·0 in the Glasgow Health Board area in this period.[5] The differences between Scotland as a whole and the west of Scotland (including Glasgow) were entirely consistent with the known higher prevalence of anencephaly and spina bifida in the west.[4]

TABLE II—*Total known cases of spina bifida and anencephaly in Scotland and area covered by Greater Glasgow Health Board, 1974-82*

	1974	1975	1976	1977	1978	1979	1980	1981	1982
					Scotland				
Spina bifida:									
No of live births and stillbirths	214	218	139	151	136	91	75	73	75
No of terminations	NA	NA	10	16	28	43	43	70	45
Adjusted prevalence	3·0*	3·2*	2·3	2·7	2·5	1·9	1·7	2·1	1·8
Anencephaly:									
No of live births and stillbirths	156	140	89	66	57	47	32	19	13
No of terminations	NA	NA	19	44	61	70	85	78	83
Adjusted prevalence	2·2*	2·0*	1·6	1·7	1·8	1·6	1·7	1·4	1·4
Prevalence of spina bifida and anencephaly†	5·2*	5·2*	3·9	4·4	4·3	3·5	3·4	3·5	3·2
					Greater Glasgow Health Board area				
Spina bifida:									
No of live births and stillbirths	56	50	22	35	25	26	25	10	20
No of terminations		1	5	7	5	8	17	21	7
Adjusted prevalence	4·0	3·5	2·1	3·4	2·4	2·5	3·1	2·3	2·1
Anencephaly:									
No of live births and stillbirths	29	34	18	11	10	9	5	3	Nil
No of terminations	1	5	11	17	26	25	17	20	19
Adjusted prevalence	2·2	2·7	2·2	2·2	2·9	2·6	1·6	1·7	1·5
Prevalence of spina bifida and anencephaly†	6·2	6·2	4·3	5·6	5·3	5·1	4·7	4·0	3·6

NA = Data not available.
* Assumes no terminations for abnormalities of central nervous system in 1974 or 1975 before α fetoprotein screening.
† Incidence/1000 total births and terminations for spina bifida and anencephaly.

TABLE III—*Number of live births with spina bifida by year of birth and year of death. (Values in parentheses are proportion (%) of affected babies dying in calendar year of birth)*

Year of birth	No of live births with spina bifida	No dying in: 1971	1972	1973	1974	1975	1976	1977	1978	1979	1980	1981	1982	No surviving end 1982
1971	236	102 (43)	14	2	2	1				1	1	1	1	111
1972	176		67 (38)	10	3	1	2		1					92
1973	169			80 (47)	19	1	1		1		2			65
1974	192				77 (40)	16	2	2						95
1975	194					67 (35)	5							122
1976	119						47 (39)	5						67
1977	135							64 (47)	4	1	1			65
1978	121								37 (31)	6		2		76
1979	81									33 (41)	2		1	45
1980	63										25 (40)	4		34
1981	67											21 (31)	1	45
1982	67												19 (28)	49

Data on mortality and survival in babies with spina bifida (table III) showed that most deaths occurred in the calendar year of birth or in the year after, the proportion occurring in the first year ranging from 31% to 47%. Averaged over five years the proportion of deaths occurring in the first calendar year was lower in 1978-82 than over the earlier period, but the falling number of survivors mainly reflected the substantial reduction in live births with the condition.

Discussion

A recent leading article in the *British Medical Journal*, commenting on trends in a number of countries,[6] pointed out that defects of the neural tube seem to have become less common in Northern Ireland, the United States, and Australia as well as in England and Wales. The increase in the number of terminations in Britain and Australia was considered to be insufficient to account for the decline in these countries, and in the United States the decline started well before 1970 and before screening was available; these data may therefore reflect a true decline in the occurrence of these conditions. In the Republic of Ireland, where there is no antenatal screening programme, the decline has been negligible.

The indications from Scottish data are that both the birth prevalence of anencephaly and spina bifida and the birth prevalence adjusted for terminations have been declining during the period considered. The introduction of antenatal screening programmes has undoubtedly been instrumental in reducing the number of live births with spina bifida and the consequent burden of disability from this condition and has also resulted in a fall in cases of anencephaly; notably, in Glasgow in 1982 there was no birth with this diagnosis. In 1976 terminations accounted for 12·7% of total known pregnancies with anencephaly or spina bifida; in 1981 they substantially exceeded the number of births and represented 62% of known affected pregnancies. The terminations reported, however, are those after α fetoprotein or other screening, and it may be that various other terminations for anencephaly or spina bifida have been performed unknown to the laboratories.

The birth prevalences of spina bifida and of anencephaly in Scotland and England and Wales increasingly converged after 1975, being 1·3 and 1·1/1000 total births respectively in 1982. This convergence may have been due to the scale of α fetoprotein screening in Scotland. In a recent study of late terminations in England and Wales it was estimated that 0·3% of terminations were performed because of increased α fetoprotein screening, and 86% of these aborted fetuses were confirmed to have neural tube defects.[7] This would represent an adjusted birth prevalence of anencephaly and spina bifida of 2·7 compared with the equivalent prevalence in Scotland of 3·2 in 1982. The data for England and Wales also showed that, when terminations after other means of diagnosing neural tube defects (principally ultrasound) were also counted, the combined prevalence of anencephaly and spina bifida increased by 15% to 3·1/1000 total births. Whether these other methods are used to diagnose anencephaly and spina bifida as often in Scotland, given the extensive α fetoprotein screening programme, is not known; but, if they are, a proportionate increase in the adjusted birth prevalence in 1982 would have been from 3·2 to 3·7. This is still considerably lower than the birth prevalence of anencephaly and spina bifida of 5·2 in 1974 and 1975 that we have reported here (and that must underestimate the true position) and supports other reports of a genuine fall in the incidence of anencephaly and spina bifida.

Our method of extracting information from routine data sources appears to be successful in providing data similar to that captured by a congenital malformation notification system in England and Wales. It can, in addition, provide data (for spina bifida) on subsequent death and, hence, the number of survivors; this permits further appraisal of the effectiveness of programmes for the prevention and treatment of this condition.

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Shredding of manuscripts

From 1 January 1985 articles submitted for publication will not be returned. Authors whose papers are rejected will be advised of the decision, and the manuscripts will be kept under security for three months, to deal with any inquiries, and then destroyed by shredding. Hence we would prefer to receive for consideration photostats or copies produced by word processor (see *BMJ* 13 October, p 942), though we do, of course, still need three copies.