

# Adolescents with spina bifida

## How they see their situation

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**Dorner, S. (1976).** *Archives of Disease in Childhood*, **51**, 439. **Adolescents with spina bifida: how they see their situation.** Forty-six adolescents with spina bifida were interviewed at home to find out how they felt about their situation. Some degree of misery was very common indeed but was more likely to be severe in girls than in boys. About half the girls had, on some occasion in the past year, felt that life was hopeless or not worth living. Since these feelings are related to their social isolation outside school, they might be alleviated by improved opportunities for contact with peers. This seems particularly important in view of the capacity of most teenagers to make reasonable relationships where the opportunity exists, e.g. at school or within the family.

Over half those who had left school were either unemployed or very dissatisfied with their job. In addition to worries about work, preoccupations about sexual relationships, sexual function, and marriage were common. About two-thirds of the teenagers hoped to get married and half of these thought they could have children. Girls were particularly worried about their capacity to conceive and boys had understandable concerns about potency. Very few had consulted anyone about this or had had advice about the genetic aspects of the condition and there is a clear need for adequate counselling to help such teenagers to distinguish between real and imagined fears about the consequences of their condition.

Until recently accounts of family life where there is a patient with spina bifida have depended on what the parents have said (Freeston, 1971; Richards and McIntosh, 1973; Walker, Thomas, and Russell, 1971). As interest has developed in older age groups, it has become possible to explore how patients themselves see their problems (Evans, Hickman, and Carter, 1974; Lorber and Schloss, 1973). Nevertheless, there is a striking lack of evidence in this area and the need for information is all the more urgent because of the increasing numbers of such patients now surviving into adolescence and beyond. Practically nothing is known of how adolescents with physical handicap face totally new issues of independence, work, and sexual relationships.

### Method

As part of a study of families with adolescents with spina bifida, which has been reported elsewhere (Dor-

ner, 1975) information was derived from interviews with 46 adolescents (21 boys, 25 girls) who were seen separately from their parents. The methodology of the study has been described previously (Dorner, 1975). Briefly, 63 families were seen at home, and parents, usually mothers, were interviewed using a semistructured schedule in order to find out about current problems. All the families had a child with spina bifida who had at some time been treated at the Hospital for Sick Children, London, and who was aged from 13 to 19 at the time of interview. The mean age was 16.4 years. In all children there was definite evidence of neurological impairment, but the severity of handicap varied. 30% of the group had minimal or mild handicap, 32% had moderate multiple handicaps, and 38% had severe multiple handicaps. Girls were more likely than boys to be severely handicapped. 8 of the 63 patients had an IQ below 70.

The adolescents were interviewed separately wherever possible using a semistructured schedule which took up to 1½ hours to complete. This paper reports the findings of the 46 interviews, excluding the 8 patients of ESN intelligence, 2 girls who refused to be seen, and a further 7 patients who could not be seen on their own.

### Findings

**Education.** Table I shows the kind of secondary school last attended and the degree of handicap. Whether or not a child had attended a day special school or residential school depended mainly on what was available locally; some teenagers were at boarding schools because they accepted pupils of good intelligence only.

TABLE I  
*Secondary school and degree of handicap*

Type of school	Mild handicap	Moderate handicap	Severe handicap	Total
Ordinary secondary	13	3	1	17
Day school for physically handicapped	0	7	7	14
Residential school for physically handicapped	2	7	6	15
Total	15	17	14	46

The 4 patients with moderate or severe handicaps at ordinary school reported their parents' insistence that they should go there and all felt it had been the right decision. The 2 adolescents with mild handicaps at a residential school for the physically handicapped were there for reasons other than their physical problems (overcrowded or stressful home circumstances). One of these 2 regretted it greatly.

Table II summarizes the general attitude to school based on the quality of the education they had received, the facilities that had been afforded, and its location.

Statistical analysis of the  $3 \times 3$  table below was not possible because of the low expected frequencies in each cell; but when comparing the attitudes of ordi-

TABLE II  
*Attitude to school*

Type of school	Definitely positive attitude	Mixed/neutral feelings	Definitely negative	Total
Ordinary secondary	7	8	2	17
Physically handicapped (day)	6	6	2	14
Physically handicapped (residential)	2	6	7	15
Total	15	20	11	46

nary school attenders first with those at day special school, and then with those at residential school, a significant difference occurs for the latter group only ( $P < 0.05$ ).

From the comments of those at boarding school, being away from home was the most common reason for their negative feelings about school. In addition, a few felt that their boarding schools were restrictive about going out or enabling contact with the opposite sex. While a natural wish to be physically normal was often expressed, and to have been able to go to ordinary school, none of the teenagers at special school seriously held the view that they could have managed at ordinary school. Most were in favour of greater integration and felt strongly about this.

**School leavers.** Exactly one-half of the group (23) had left school at the time of interview; the work situation of the total group of 63 is noted elsewhere (Dorner, 1975), and it should be remembered that the situation of those with intellectual retardation is not included in the following analysis.

Eight out of the 23 school leavers were in full-time open employment; 7 more were engaged in full-time further education including 2 at university. 6 were not working. One was working part-time and one was in sheltered work. The last 2 were of limited intellectual ability though above the ESN range. The reasons for unemployment varied. There were 2 whose physical condition prevented it (severe trophic ulcers); one girl clearly preferred to stay at home with her mother, whom this also suited. One boy had just left his job because of bullying at work, and 2 teenagers were unable to find work because of problems with stairs.

The teenagers were asked what they would ideally have wished to do on leaving school. Not unusually for handicapped groups, many responded that they wanted to work with children or in hospitals. Thus girls often wanted to be nurses and boys to work in hospital laboratories. One boy who had had considerable problems because of urinary infections had long intended to work in the field of water pollution! Less handicapped boys wanted to express their relative absence of disability in a job that required some physical exertion. There were only 3 out of 23 who had achieved their ambition but a further 7 who had some prospect of doing so and were pursuing appropriate further training or education (including one young man studying medicine). The remainder (13) had little or no prospect of achieving their ambition, which was sometimes acknowledged to be unrealistic. In general teenagers with only mild handicap and modest

aspirations are likely to be satisfied by their work situation and good educational and intellectual status may enable more severely handicapped adolescents to work towards attaining their goal.

**Social relationships at school or college.** Inquiry was made about friends at school or college or at the last school they had attended if no longer in full-time education. Table III indicates that

TABLE III

*Friends at present/last school or college*

	Adequate/ good social relation- ships	Limited, e.g. close reliance on one friend	No close friends	Total
Special school/ college	9	15	3	27
Ordinary school/ college attenders	10	8	1	19
Total	19	23	4	46

there were relatively few (4) who had no real friends at school or college and that there is no significant difference between those at special school or college and those at ordinary establishments.

While this picture of social relationships at school is fairly encouraging, it is difficult to evaluate how intimate friendships actually were. Certainly there seemed relatively little confiding about personal preoccupations and many friendships may have been fairly superficial.

Nineteen out of 46 teenagers admitted to being teased at school but only 5 of them were seriously distressed by it. By this age being teased about lack of mobility, etc., does not seem too distressing. Girls were more likely than boys to admit to being teased, but the situation is reversed for bullying in that of 5 who were bullied, 4 were boys. Very few of those who were teased or bullied had developed ways of verbal or physical retaliation. Neither teasing nor bullying was related to the kind of school attended.

**Social relationships outside school.** While the type of school does not appear to be related to social relationships in school, if one looks at relationships outside school there is a significant difference between special and ordinary school attenders, though not between special day or residential school pupils (Table IV).

TABLE IV  
*Friends outside school/college*

	Good/ adequate social relation- ships	Limited	No friends	Total
Special school/ college (day or residential)	4	8	16	28
Ordinary school/college	7	8	3	18

$\chi^2 = 7.83, \text{d.o.f. } 2, P < 0.02.$

Thus social isolation was much more likely outside school or college if the patient attended or had attended a special school or college. It seems that it is lack of opportunity rather than difficulty in establishing relationships that is crucial since they are able to have relationships at school where there the opportunity exists. It cannot be concluded from this that being at special school in itself leads to isolation at home since one difference between children at ordinary school and at special school is the severity of mobility problems and these are closely associated with social isolation (Table V).

TABLE V  
*Social isolation and mobility*

	Some/severe social isolation	Not isolated	Total
Mobility problems	21	1	22
No/mild mobility problems	14	10	24
Total	35	11	46

$\chi^2 = 6.77; P < 0.01.$

However, all 4 patients with moderate or severe mobility problems who had been at ordinary school had at least one friend outside school, compared with only 6 out of the 18 special school attenders with similar mobility problems and this difference is significant  $P < 0.025$  using Fisher's exact test). While this may mean that being at special school does limit the opportunity for peer contact at home irrespective of the degree of mobility, it is also possible that what determines the attendance of handicapped children at ordinary school includes some personal or family characteristic that also facilitates social relationships.

**Depression.** Each adolescent was asked whether he sometimes felt miserable and unhappy to the extent of being tearful or wanting to get away from it all. 85% reported having felt like this. This compares with nearly half of a group of normal 14½ year olds interviewed in a study on the Isle of Wight (Rutter *et al.*, 1976). Girls in the present study were more likely than boys to report frequent misery, though almost as many boys (81%) as girls (88%) sometimes felt miserable (Table VI).

TABLE VI  
*Sex of patient and feelings of misery*

	Frequently miserable	Sometimes miserable	Not miserable	Total
Boys	4 (19%)	13 (62%)	4 (19%)	21
Girls	14 (56%)	8 (32%)	3 (12%)	25
Total	18	21	7	46

Only one boy, but nearly a quarter of the girls had had suicidal ideas in the past year, and one girl had made a suicide attempt. In a study of normal adolescents on the Isle of Wight, 7.3% of boys and 8% of girls aged 14½ had suicidal ideas (Rutter *et al.*, 1976). Half the girls in the present study had on some occasion felt life was hopeless or not worth living, but less than one-quarter of the boys had felt this.

It is clear that misery, or similar feelings, are very common indeed in the whole group and that they are more severe in girls than in boys. One possible cause is that the girls tend to be more handicapped than the boys, but though there is a trend, the association between feelings of misery and mobility problems is not significant ( $\chi^2 = 3.29$ ,  $P < 0.1$ ). Nor is there any association between misery and overall severity of handicap. For girls, but not for boys, there is an association between misery and social isolation. 10 out of 13 isolated girls admitted to feelings of misery compared with only 4 out of 12 nonisolated girls. This is a significant difference ( $P < 0.05$  using Fisher's exact test). One interpretation, therefore, is that since isolation and mobility are associated (Table V) girls are emotionally affected by the consequences of their mobility problems, i.e. social isolation where it occurs, rather than by the lack of mobility itself. However, it is just as possible that social isolation is a result or sign of feeling miserable rather than its cause.

Boys, though more mobile, are no less likely to be isolated than girls, and in a previous study there was some suggestion that they are more affected

by the presence of urinary appliances (Dorner, 1976). Social isolation appears less likely to make them miserable or to admit to feeling miserable at interview.

**Family relationships.** The teenagers usually felt they had reasonably good relationships with their parents in terms of doing things together and finding them easy to talk to. The most common complaint was that parents were 'too protective' or did too much for them. Altercation occurred less frequently than in the group of normal Isle of Wight 14½ year olds (Rutter *et al.*, 1976). Compared with about one-third of their group, only 6 out of 46 spina bifida adolescents admitted to arguments with their parents. In all 6 cases it was with the father, but about nothing very specific. On the other hand there were only 3 of the remainder who felt that their parents fully understood how they felt. At interview a substantial proportion admitted they had been able to talk to someone outside the family about matters they could not openly discuss at home. Sexual preoccupations and feelings of misery were the most difficult topics to discuss in the family.

Relationships with sibs were also apparently free of serious difficulty. Only in 2 cases was frequent argument reported, and in some cases it was clear that some brothers and sisters, often adult, were energetic in the efforts to spend time with the handicapped sib.

**Attitude to condition.** There were relatively few adolescents who had a good understanding of the nature of spina bifida and almost all of them said they would like to know more but felt inhibited about saying so when attending for hospital appointments. The exceptions were one young man who was studying medicine and one girl whose father was a doctor. 2 others had a good understanding but still wished to know more. Of those whose understanding seemed good the following is a randomly selected example. 'Somewhere along the spinal cord it doesn't fuse. The nerves come out in a bump. The bit below the bump is partially or completely paralysed. I know you can also get hydrocephalus. I've heard about the potato blight theory. I don't think it's been proved.'

Four teenagers produced descriptions of the condition with such detail. A further 8, whose understanding was defined as adequate, gave accounts of which the following was a typical example. 'I'm paralysed from the waist downward because my nerves are damaged at the base of my spine.' There were 24 whose understanding seem-

ed limited ('your spine is unjoined. I don't know why it stops you walking. I'd like to know more'). The other 10 patients were unable to give any description of the condition, e.g. 'I don't know what spina bifida is. I've never asked anyone'.

**Sex and marriage.** All except one boy, aged 13, acknowledged an interest in the opposite sex, but as seen in Table VII very few had been able to establish relationships with the opposite sex. Homosexual interest was not investigated.

Of those currently having a relationship with someone of the opposite sex, all were fairly mobile, i.e. could walk without calipers, but one girl and one boy had urinary diversions. This presented a considerable worry to the boy who had been unable to tell his girlfriend about it as he had been rejected by a previous girlfriend because of it. Interviews with other boys with urinary appliances confirmed this as a serious preoccupation in their aspirations towards the opposite sex. While the results of the interviews with the 46 adolescents showed that those with relatively little handicap are most likely to establish relationships with the opposite sex, they omit 3 girls out of the total of 63 whose parents were interviewed, who were engaged to be married despite severe urinary, mobility, and other problems (Dorner, 1975).

Thirty (65%) out of the 46 teenagers thought they would be able to marry and wanted to do so. A further 5 had doubts but envisaged marriage. Of those who definitely hoped to marry, about half thought they would be able to have children, including a number of boys and girls with urinary and locomotor problems. It is clear that these aspirations are unlikely to be fulfilled for most of them (Evans *et al.*, 1974). As many boys as girls envisaged marriage but girls were much more preoccupied with this question than boys. The great majority of girls said they thought a lot about whether they could have children and wished to do so. They were much less concerned about the advisability of doing so in terms of their capacity

for adequate care. While some had discussed this with a doctor, few had done so in detail, and most had simply been told that there was probably no physical obstacle to their conceiving. Only one girl had an accurate understanding of the increased risk of her having a child with the same or related condition (Carter and Evans, 1973). Most inaccurately denied that there would be any risk.

In contrast to girls, boys were less preoccupied with marriage and were more concerned to know whether they could be potent. 9 out of 21 boys claimed that they had erections but it proved impossible to elucidate reliably in a single interview how many of them had ejaculations. This was partly because it was not always certain whether the enquiry about this was fully understood and partly because some boys did not themselves seem certain.

### Discussion

There seems little doubt that many problems beset these adolescents with spina bifida and that they may be even more severe for the younger, more handicapped patients who have since survived in greater numbers, some of whom have now reached early adolescence. At its most gloomy, the picture is one where the condition is associated with severe social isolation, frequent misery and depression, especially in girls, with problems of finding satisfying work or indeed any work at all, with preoccupying worries about the future and with the prospect of unfulfilled wishes in relation to marriage and children. The picture is brightened to an extent by the apparently good relationships with parents and sibs that were usually reported and the ability to establish relationships at school.

There are, however, grounds for arguing against the inevitability of this situation. In the first place, it should be emphasized that there were some adolescents who had made an adjustment to their situation that might reasonably be described as adequate or better. 11 teenagers appeared to be

TABLE VII  
*Heterosexual relationships*

	Boy/girl friend (current)	Boy/girl friend (ever)	Relationship involving kissing	Sexual intercourse	No heterosexual relationship
Boys	4	5	5	0	16
Girls	2 (one engaged)	8	7	1	17
Total	6	13	12	1	33

leading lives where reasonable peer and family relationships were maintained, and experienced only the occasional misery that is probably common in normal teenagers. These 11 teenagers were reasonably positive about school and fairly optimistic about their working future. While the future may well contain disappointment, 7 of these 11 have had some on-going relationships with a member of the opposite sex and the other 4 were not upset by its absence. 4 of the 11 whose adjustment was satisfactory were minimally handicapped, i.e. were fully continent and walked with nothing more than a limp; 3 more had urinary appliances with only mild mobility problems; and the remaining 4 had both urinary appliances and mobility problems, i.e. wore calipers or were in wheelchairs. Thus it is not impossible for youngsters with moderate or severe handicap to adjust to their situation.

A further argument against the inevitability of serious problems is that very variable help had been offered for the difficulties that have been described. Only one of the considerable number of girls whose depression probably warranted some form of psychiatric help had actually received any. A number of teenagers were dissatisfied or confused about the career guidance they had received, or had received no such help. A very small minority had had the chance to discuss their sexual potential or to have worries about future children alleviated. In view of the inaccurate knowledge that prevailed, it seems essential to provide this facility. Some success has been achieved combining a didactic approach with free discussion, some of the time with boys and girls separately, and some of the time together. In addition, it is necessary to offer the opportunity for individual counselling where this is appropriate because of the personal nature of the concerns. Organizations concerned with the sexual problems of normal adolescents may have a role to play in this respect.

Although some teenagers had used various social

facilities, e.g. clubs, and others had failed to take advantage of such facilities, there was a substantial number for whom no efforts had been made by outside agencies to provide contact with their peers outside school. It seems essential that energetic efforts should be made to do so. Almost all the teenagers interviewed do have the capacity to make relationships with their peers. This conclusion seems justified by the small number who had no friends at school. If they were able to make more contact outside school, it is possible that the misery found so often in conjunction with social isolation could be alleviated. Most teenagers expressed the wish that such contact should be with able-bodied as well as with handicapped people and reported very favourably on PHAB courses (Physically Handicapped and Able-Bodied). The author has had the opportunity to participate in weekend courses of this kind and to witness the capacity both of the handicapped and able-bodied adolescents to relate with enjoyment and sympathy.

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