

Psychological and Social Problems of Families of Adolescent Spina Bifida Patients: a Preliminary Report

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This paper reports some of the psychological and social difficulties experienced by families with an adolescent spina bifida patient. The names of surviving children born between 1953 and 1959 were obtained from the records at the Hospital for Sick Children, London, and so far 37 families (about three-quarters of the total) have been interviewed. In one further case the mother refused to be interviewed. One mother was no longer alive.

Information was obtained from a semi-structured interview with one or both parents lasting for about two hours. The teenage patients were also interviewed more informally, and school reports were also available.

In all but one case arrangements for continuing care of the adolescent within the family setting have been maintained. In the one case where this was not so, the mother who refused to be interviewed informed me that her daughter was in long-term institutional care. The children who had gone away to residential schools (almost one-third of the total) had done so because of the lack of appropriate provision locally rather than because the burden of day-to-day care had become too great, and their parents made considerable efforts to visit them frequently.

Marital breakdown did not appear to be more prevalent than in the general population, only four of the 36 mothers interviewed being divorced or separated from their husbands. There was definite marital disharmony in a further five families, but this was more clearly related to psychiatric illness in one of the parents rather than to stress brought about by the patients' problems.

On the surface, it may be concluded that the families are continuing to cope with the situation, but it became clear that many were doing so at considerable cost to their psychological and social lives. Family routine is often disrupted by problems associated with hospital attendance. Using measures such as total time taken, financial loss and problems with transport, 11 families suffered major disorganisation of routine. Another 11 families experienced minor difficulties, but the remaining 15 families had had little or no difficulties with hospital visits during the year before interview.

Families were also often limited in their social lives. For example, the parents of one 14-year-old girl could not leave her unattended because she became upset at being on her own and was very difficult with anyone who agreed to be with her while the parents were out. A few children had never in their lives been left on their own at home for more than one hour. Such major disruptions to their social lives were reported by 15 families and a further 15 were inconvenienced to a minor degree.

The adolescents themselves often had severely restricted social lives. While some contact had been maintained with their normal peers in the past, at the time of interview the parents

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often felt that this no longer happened. 15 patients were reported to be severely isolated in terms of visits by other children or their visiting other children's homes; indeed, some children had never been to the houses of other children and had themselves been visited only once or twice in the previous year. Of the children in residential schools, about one-quarter appeared to have been visited by or to have visited other children with relative frequency, but even they were reported to have fewer friends than their physically normal peers, or no close friends at all.

Maternal psychological stress was also investigated at the time of interview. Of 36 mothers, 10 had been to their family doctors in the previous year with definite psychiatric problems and a further seven with what were probably psychological complaints. 14 of the mothers were on tranquillisers or anti-depressants at the time of interview and had been for an extended period. 19 of the 36 mothers complained of sleep disturbance, loss of appetite, anxiety, lack of energy or depression, which is a higher proportion than that occurring generally in mothers of their age-group. Depression seems to be the most common complaint in this situation, just as it is reported to be in mothers on the birth of a handicapped child.

Husbands were less affected by lasting psychological stress, but the wives often commented on their own concern to protect their husbands from distress. This may well relate to the earlier finding that most of the marriages were basically stable.

The findings described so far are the major ones to emerge from this study, but they are not the only ones. For example, housing was only occasionally reported as being a problem, but when it was the strain was severe.

On the positive side, most of the parents were grateful for the medical and surgical care their children had received. They were also generally satisfied with the schooling their children had received. Five parents were severely dissatisfied and another five had some reservations, but 27 parents had no serious complaints, even though two-thirds of the children were in special schools.

It was evident from the interviews that the parents made a clear distinction between their satisfaction with the medical services provided and their dissatisfaction with the information they had been given about their child's condition. Marked dissatisfaction was expressed by almost one-half of those interviewed and only one-third expressed themselves as being reasonably satisfied.

In addition to the need for more information about their child's condition, a need for more specific genetic counselling also emerged. This was most frequently expressed by mothers when discussing their daughter's future marriage and children.

It was also clear that a considerable problem existed in relation to local welfare services, many families having had little or no contact with either statutory or voluntary organisations. Even among those who had such contacts, more long-term supervision seemed to be indicated, for purely practical problems were magnified by worries over the child's future independence, job prospects and sexual capacity.

When this study has been completed, an important point will be to see whether there are any characteristics shared by the families with severe difficulties which differentiate them from others in this group with spina bifida adolescents.

SUMMARY

This preliminary report discusses the psychological and social problems of families with an adolescent spina bifida patient, 37 of whom have been interviewed to date. There was no more marital breakdown or disturbance than in the general population, but in the majority

of families there was disruption to a major or minor degree of their psychological or social life. The adolescent patients themselves also led severely restricted social lives. More than one-half of the mothers had some symptom of psychological disturbance, the most common being depression.

RÉSUMÉ

Problèmes psychologiques et sociaux des familles d'adolescents atteints de spina bifida— rapport préliminaire

Ce rapport préliminaire discute les problèmes psychologiques et sociaux des familles d'adolescents atteints de spina bifida, 37 d'entre elles ayant été interrogées jusqu'à ce jour. Il n'y a pas plus de rupture conjugale ou de perturbations que dans la population générale, mais dans la majorité des familles, il y a une perturbation dans leur vie psychologique ou sociale à des degrés variés. Les adolescents malades eux-mêmes ont des vies sociales fortement refermées. Plus d'une moitié des mères se plaignent de quelques signes de perturbations psychologiques, le plus fréquent étant la dépression.

ZUSAMMENFASSUNG

Psychologische und soziale Probleme von Familien mit heranwachsenden Spina bifida Patienten: ein vorläufiger Bericht

Dieser vorläufige Bericht diskutiert die psychologischen und sozialen Probleme von Familien mit einem heranwachsenden Spina bifida Patienten; 37 solcher Familien wurden bis jetzt befragt. Die ehelichen Beziehungen waren nicht häufiger zerbrochen oder gestört als im allgemeinen Bevölkerungsquerschnitt, aber bei der Mehrzahl der Familien war das psychologische und soziale Leben mehr oder minder zerrüttet. Die heranwachsenden Patienten selbst hatten nur sehr eingeschränkten sozialen Kontakt. Mehr als die Hälfte der Mütter klagte über eine psychologische Störung, die häufigste war die Depression.

RESUMEN

Problemas psicológicos y sociales en familias de adolescentes con espina bifida: comunicación previa

Esta comunicación previa discute los problemas psicológicos y sociales de familias con adolescentes con espina bifida de las cuales 37 han sido entrevistadas. No había un mayor problema marital que en la población general, pero en la mayoría de las familias había una disrupción en su vida psicologica o social en un grado más o menos acusado. Los pacientes adolescentes llevaban también una vida social marcadamente restringida. Más de la mitad de las madres se quejaban de algún sintoma de alteración psicológica, siendo la más frecuente la depresión.