Contemporary Themes

Counselling the parents of handicapped children*

DAVID C TAYLOR

Abstract

The parents of handicapped children have to adjust to a wide variety of emotional and psychological problems when first confronted with the failure of their reproductive expectations. Counselling is a formal procedure or transaction in which both counsellor and parents aim to find a mutually acceptable plan of adjustment. Parents may need support to cope with their own personal inadequacies as well as with the needs of the child. Counselling should be a continuous process, in which the parents can learn to accept the child as a different rather than as a lesser person.

Introduction

The parents of handicapped children will have many conversations about their children and about their problems, but when they turn to a professional for help through counselling they are looking for something more. Counselling is a formal procedure in which the counsellor is entrusted by the parents to bring wisdom, or special knowledge, to devising a mutually acceptable plan of adjustment. Its purpose has to be agreed and understood by both parties for its aim to be achieved. It is not the process of a single (at least not a brief single) transaction, and since the counsellor, the parents, and the handicap are variables, the synthesis they achieve is unique. The problem of measuring the effect of counselling is to know what should be measured and when. Good adjustment is relative and not necessarily immediate.

Reproduction and its frustration

Although reproduction is taken largely for granted it is actually a rather perilous process. A substantial proportion of pregnancies come to nothing in their very early weeks, and even by the time of normal parturition mortality among the newborn is high. The handicapped child is the living reminder of the inefficiency of that reproductive process and will inevitably be less than was hoped for. What was hoped for depends largely on why people decide to have babies at all. Even mothers who were not too sure that they did want a baby will look for some return on the investment of their labour.

Although many people do not actually formulate why they have children, there are a variety of reasons why they do. Children represent the satisfaction of social expectation; they

provide for the parents' need to manifest their capacity to love and care; they allow the continuance of the culture; they are a repository of their biological substance; they represent the synthesis of two persons; and they are an adornment or at least a useful chattel. The handicapped child disappoints most of these purposes; he fails from the start to take the place of the "fantasied" child. This "fantasied" child is difficult to dispose of; the actual child does not replace him and yet he stands in the way of grief. Parents in the initial stages of shock somehow recognise that it would be easier to come to terms with a dead child than with a diminished one. Not only is the child less than was hoped for but is the positive realisation of their worst fears. The child will represent their failure to achieve the social expectation. He will test their capacity to love and care and will offer no continuation of their cultural values. He will be a parody of their biological substance and their synthesis—not an adornment but a stigma, not a chattel but a burden.

Breaking the news

Whoever breaks the news to parents that their child is handicapped has a heavy and unenviable burden and is often the person on whom they vent their powerful emotions. Much of what is said will be denied and many parents will protest that the news was clumsily given, as it sometimes is.

Information should be given as soon as possible after it is available, although finding a figure of trust soon after a birth is not always easy. The obstetrician may not "know" the parents at all. The paediatrician is in an anomalous position since he actually represents the putative sick baby. But the counsellor should at least be seen to be wise and experienced. The news should be given to both parents together and in private. The information should be thorough, efficient, and as concerned as possible with the cause of the handicap, but ignorance should not be concealed. Wherever possible bad news should be tempered with hope. Counselling is not a monologue, and despite the fraught situation the parents must be given the opportunity to talk until the problem is clearly understood. Most of the information will probably not be assimilated and most of the shock and anxiety will not be apparent. The counsellor will have to hide any irritation at having to go over it all again and in great detail at a later date. He will also realise that sharing information alters his relationship with the parents, which must be rebuilt if the best possible adjustment to the problem is to be achieved. The work of re-establishing the relationship must, therefore, be done by the counsellor by actively retaining contact, resisting rejection, and ensuring continuation by all possible means.

Adjustment

The stages of grief are shock, denial, numbness, depression, and, finally, adjustment. The passage through these stages takes

*Shortened version of a lecture given at a course organised by the MEIU of the Spastics Society, 21 November 1981.

time and continued contact is essential. For the paediatrician his routine of caring, managing, and investigating provide this contact. For other professions too the actual practice of their skills acts as a firm basis for counselling.

Coming to terms with a problem means agreeing on an adequate script to account for a tragedy; it may require negotiation over several years. The script need not coincide perfectly with the facts to be "good enough." Along with establishing cause can come establishing blame. It is helpful to parents if blame can be projected (exteriorised)—even though it is not actually true—rather than left interiorised as guilt. One of the torments of ignorance is that parents are left in limbo with their anger, unable to lay it comfortably on to God, or fate, or the doctors. Compensating is a part of adjustment although in some parents the devotion and dedication can be overwhelming, blinding parents to the prospect of better adjustment for the whole family. Feelings of inadequacy and rejection are dangerous, not just because of the consequences to the child but because it is, for the parents, a second failure. Negotiating participatory management for children in the care of others, regular visiting, and visits home, therefore, is not just beneficial for the handicapped child but is a defence against secondary guilt in the parents.

Parents' responses and needs

Since counsellors, parents, and handicaps vary, needs vary accordingly. Some parents can be bound up with their methods of coping and with their capacity to cope. Should we allow them to sacrifice themselves for the child? Should we allow them to sacrifice the best interests of the child by meeting their own needs? Should the inadequacy of our resources direct us towards encouraging parents to battle on with their child at home to what seems their mutual disadvantage? Should parents already taxed to the extreme be offered the further gratuitous insult of psychiatric advice?

The experience of tragedy may bring out great and previously unknown resources and strengths within a family and within parental relationships. It may combine them in a creative way or it may uncover or resurrect deep traumas and deficiencies hitherto undisclosed, which may otherwise have remained undisclosed. Trauma may act like a psychic stress/exercise test or it may only cause further deterioration in mental health or manifest difficulties in general coping. It may sow the seeds of dissent within a marriage or act to reap the harvest of former ills. Counselling should, therefore, give parents the opportunity to face those issues within themselves, which great trauma has brought into prominence. Unfortunately, our culture still makes it difficult for people to receive psychological counselling without

guilt. This is another reason why more health care professionals should be psychologically sophisticated. On the whole perhaps people are rather too brave.

Continuing assessment

Unlike the major handicaps apparent at birth or soon after, some become evident to parents and attendants only over a period of time. Since, initially, there is no adequate information on which to prognose an outcome, counselling has to be a much more patchy affair. Information is eased out piecemeal as the child serially fails its later milestones. This is so often the case in the more destructive seizure disorders of childhood. For these children periodic comprehensive review as inpatients, with their mothers, serves as a basis for stocktaking and further counselling. Such assessments have become the business of the special assessment centres. Sadly, the psychiatric input into them has become separated from the services for the mentally handicapped, and instead of acting as a pervasive presence the psychiatrist reports in a vein similar to the ophthalmologist and the biochemist. The transfer of care from the primary paediatrician to the mental health service, both for the young severely handicapped and for adolescents, needs serious consideration. The sudden removal of the extensive child care service in exchange for community care for the mentally handicapped often produces a major upsurge in distress for all concerned.

Conclusions

What then is the nature of the type of adjustment to which care and counselling from the earliest diagnosis are aimed? Firstly, it must be made clear that there is no necessary correlation between the existence of a handicap and any particular type of behaviour or distress. While development may be restricted and greatly more hazardous in behavioural terms than for the normal child, particular problems are not inherent in the diagnosis of handicap. Secondly, no predetermined limits should be placed on the child's capacity to relate, to communicate, to develop bowel and bladder control, to move around, or to experience pleasure. Thirdly, fabricating behaviour disorders or disrupting behaviours by the injudicious use of drugs should be avoided and stigmatising behaviour eliminated as soon as possible. Fourthly, since the general health, and especially the central nervous system, of the handicapped child is very vulnerable, continuous paediatric care is desirable. Lastly, parents should be encouraged to learn to accept the handicapped child as complete, albeit different, rather than as a failing or partially failing normal person.

After a pulmonary embolus that causes bilateral pulmonary opacities what are the special circumstances under which a normal ventilation perfusion lung scan can be obtained three days later? Are there any published references?

The radiographic findings of a pulmonary embolus may be either hypertranslucency due to under perfusion or areas of consolidation, representing infarction, due to oedema and haemorrhage. In the first case a ventilation-perfusion (V/Q) study will show a mis-match due to reduced perfusion compared with relatively normal ventilation. Ventilation, however, will also be reduced in the first four hours after the event. As it is rare to perform a ventilation-perfusion study within this period, this fact is not of practical importance. Secker-Walker¹ found that normal ventilation and perfusion studies imaged in the anteroposterior, posteroanterior, and both lateral views virtually exclude a pulmonary embolus, and that the rate of recovery is variable. A large proportion of recovery occurs in the first three to four days, and a few patients show complete resolution within 24 hours. Interestingly, however, in a series of 74 patients repeat studies recorded that patients' scintigrams first returned to normal after 11

days.² In addition, 35% of patients in the series showed new "cold spots." Tow and Wagner³ showed that recovery had no direct relationship to the size of the initial defect. Minimal lesions took up to two weeks to clear. Intermediate lesions could resolve within eight days, while cold areas due to severe lesions persisted for up to 60 days. It is recognised that proximal emboli may fragment and pass into the periphery of the lungs as microemboli. They may be so small that they are beyond the resolution of the imaging system. Thus it can be impossible to distinguish this situation from complete recovery. As a pulmonary infarct resolves more slowly than a pulmonary embolus, taking more than three days to clear,⁴ it is unlikely that a ventilation-perfusion study would be normal after three days in the presence of a pulmonary infarct.—M C PEARSON, consultant radiologist, London.

¹ Secker-Walker RH. Pulmonary nuclear medicine. In: Gottschalk A, Potchen EJ, eds. *Diagnostic nuclear medicine*. Baltimore: Williams and Wilkins, 1975:351-60.

² Secker-Walker RH, Jackson JA, Goodwin J. Resolution of pulmonary embolism. *Br Med J* 1970;iv:135-9.

³ Tow DE, Wagner HN. Recovery of pulmonary arterial blood flow in patients with pulmonary embolism. *N Engl J Med* 1967;276:1053-9.

⁴ Castleman B. Pathologic observations of pulmonary infarction in man. In: Sashara AA, Stein M, eds. *Pulmonary embolic disease*. New York: Grune and Stratton, 1965:86-92.