Clinical Topics

Approach to the management of children with malignant disease in one district general hospital

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The family of a child with cancer is under considerable stress. Great emphasis has always been placed on the medical aspects of the treatment of malignant disease, but there is also considerable psychiatric and social morbidity among parents and siblings.¹

With the aim of reducing this morbidity the children's haematology clinic at the Royal Berkshire Hospital, Reading, has evolved over the past 10 years. Many ideas have come from the experiences and feelings of the parents, and the clinic team aims at providing emotional support for the whole family as well as dealing with the medical problems. This support continues even if the child is considered to be cured, because the family may experience anxiety and stress for many years. Similarly, bereavement counselling¹ is given, again often prolonged, because some parents find that the team members are the only people to whom they can talk about their lost child. The weekly clinic forms the cornerstone of our management.

The staff

The clinic is staffed by a team of five. Four are doctors—a consultant paediatrician, a consultant haematologist, a senior registrar in haematology (whose appointment is for two years), and a paediatric registrar (appointed for one year). A team of four doctors allows adequate cover for holidays and provides continuity of care, although in common with other workers² we have found that individual families often relate best to one particular doctor. The team is completed by a senior social worker, who sees all the families and gives practical help and emotional support when necessary.

Parents and children coming to the clinic never see a doctor to whom they have not been introduced unless at least one regular team member is also present. They are also told that they can always contact someone who knows them and their child. The case notes are all kept in the clinic and are therefore readily available at all times.

The clinic

The clinic is held on Monday mornings in the paediatric outpatient department. This is a self-contained unit specifically designed for family consultations. The waiting area is liberally provided with toys and the children all play together. Refreshments are always available. There are two regular staff nurses, whom the families get to know. There are no fixed appointments, but most families arrive between 0930 and 1030.

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Most patients have malignant disease. Currently 15 have acute leukaemia in various stages of treatment (including five who are off treatment), eight have solid tumours, and five have other haematological disorders.

The parents find this time, when they can meet others with similar problems, very useful. Those who are still shocked by the news of the diagnosis see children who are well established on treatment or who have completed treatment and remain in remission. The social worker is present in the waiting/play area throughout the morning and is available for an informal chat, or can see parents privately in one of the consulting rooms if necessary. This close involvement is particularly valuable since many parents feel that attention to their personal problems might distract the doctor from the medical management of the child.

Although the atmosphere in the clinic is as relaxed and informal as possible, the routine for the children is always the same. They are examined completely at each visit and so become accustomed to this procedure. Venepuncture is performed by a member of the medical team using a 23G Butterfly needle (Abbott), and chemotherapy, when necessary, is given at the same time. Any treatment required more often than once a week is always given by one of the team members. The child is never dealt with by someone he or she does not know other than in exceptional circumstances.

On the Friday preceding the clinic the drugs are ordered at a medical staff meeting. Consequently the children and their parents do not have to queue at the pharmacy. The team meets again after the clinic to discuss any new problems.

The individuality of the patients and their families is given particular emphasis. All the children are sent birthday cards and given Christmas presents. At Christmas a special party is organised by the paediatric ward staff, who invite all the children attending the clinic, together with their brothers, sisters, and parents.

Procedures

All lumbar punctures, bone marrow aspirations, and, in the case of younger children, radiotherapy, are performed under general anaesthetic. Lumbar punctures and bone marrow aspirations are carried out in the treatment room of the children's ward, which is adjacent to the outpatients' department, and the child wears everyday clothes. The anaesthetic is administered by one of the two senior registrar anaesthetists who provide the anaesthetic service for the clinic. Again, the aim is that the children should see a familiar doctor. They know that they can go home as soon as they feel well enough—often within an hour and always on the same day.

Usually an intravenous induction agent is used, without premedication, and induction normally takes place with the child sitting on a parent's lap, perhaps being told a story. The parents may stay and watch the procedure if they wish, though we find that most prefer to go for a cup of coffee and return when their child is waking up.

Parents are telephoned later the same day with the results of bone marrow examinations and blood tests and are told of any necessary changes in treatment. If a leukaemic child has relapsed one of the doctors and the social worker visit the child's home that evening to break the news. We consider that it is essential to see parents on their own territory to enable them to discuss the implications of relapse, which is in many ways as serious as the initial diagnosis.

Initial explanation and parental education

When leukaemia is diagnosed, the parents are initially seen by at least two doctors—if possible the two consultant members of the team. Father and mother are seen together and away from their child so that they need not be afraid of showing emotion.³ The initial diagnosis comes as a great shock to all parents, and sometimes only the single word "leukaemia" is remembered, but ample time is made available for further discussion over the next few days. The social worker is introduced as a member of the team after this first interview, and the general practitioner is contacted as soon as possible so as to involve him fully.

Parents are also given a booklet to read—either *Leukaemia—A Booklet of Advice for Parents* (Medical Research Council Leukaemia Trials Office) or *Leukaemia—A Guide to Treatment and Care* (Leukaemia Research Fund). They are encouraged to keep a list of any questions that come to mind, and to bring this when they next attend.

Patients with solid tumours are often diagnosed at a regional or supraregional centre, where treatment is planned and co-ordinated. Radiotherapy, where appropriate, is usually given at Reading, where the two radiotherapy consultants have a particular interest in the treatment of children with malignant disease.

Parents are usually keen to be involved and to learn as much as possible about their child's illness. Informal evening meetings, often with a guest speaker, attract the support of most parents from the Reading clinic and some from other clinics within a 50-mile (80-km) radius. At these meetings, which are held in a short series every few months, a range of topics from bone marrow transplantation to the care of the dying child is discussed. A tour of the laboratory usually proves particularly popular. We have found that many of the children's schoolteachers wish to be included, and parents sometimes invite them to the evening meetings.

With the parents' permission, the head teacher of the child's school is informed of the diagnosis and is given a brief explanation of the disease, its prognosis, and treatment. Schools are also asked to warn parents if infectious diseases are prevalent.

Role of the family doctor

Childhood malignancy is rare. By the very nature of the condition, much of the management must be based on the hospital. The intimate knowledge of the family possessed by the general practitioner, however, is often invaluable in recognising pre-existing problems and identifying a family at particular risk from any additional stress.

Relapse and bereavement

If a relapse occurs the parents need even more help. They all know that the chance of a cure is much diminished, and the behavioural changes after relapse in the central nervous system may be particularly distressing. If readmission to hospital is needed it is always to the ward on which all procedures have been carried out in the past.

When the illness becomes terminal, some parents prefer to nurse their child at home. This requires great courage, and considerable support is usually needed. The social worker visits daily and, after consultation with the general practitioner, medical team members will go to the home as often as necessary.

Involvement of hospital staff does not end with the death of the child. Many parents ask for representatives of the team to attend the funeral. Retrospective feelings of guilt and inadequacy are common, and a meeting with one of the consultants to deal with these and other questions is often helpful.

The social worker continues to visit the family at increasing intervals, and always on the first birthday after the death, around the time of the anniversary, and at Christmas. She is always available to the family and has, on occasion, been contacted again several years after the death of a child.

Conclusion

It is difficult to quantify the success of this supportive approach. Certainly we find that our patients often look forward to their visits to the clinic and are rarely reluctant to submit to examinations or procedures. This must reduce the stress for the

accompanying parent. Many parents have also commented that they found ready access to the social worker extremely helpful.

In a study of 59 families¹ Peck found that 42% of mothers needed at least short-term psychiatric treatment, with 10% requiring inpatient treatment. Five women attempted suicide. Thirty-five families had serious marital problems related to the child's illness and death.

Since the beginning of 1978, 40 children with malignant disease have been treated at the Reading clinic. No parent has needed formal psychiatric treatment, although eight have discussed feelings of depression with the social worker. Eleven couples have experienced marital problems as a result of their child's illness but no family has broken up. Nine families have experienced behaviour problems with siblings.

Even the strongest family units find it difficult to cope with a seriously ill child. Many are too proud to ask for help, especially if they assume, as some do, that their medical attendants are interested only in the child's physical illness and its immediate treatment.

We think that by making our interest in the whole family obvious and by providing ready access to psychological support we have made progress in alleviating this general distress, and we hope that we shall be able to reduce the well-recognised incidence of family disruption caused by the stresses of caring for a child with malignant disease.

The original idea for setting up the clinic came from Dr Hope Forsyth, paediatric registrar 1971-3. We are grateful to Sister Laura Cox for her unfailing interest in the children and their families and to Dr A Kircher and Dr J Bunting of the radiotherapy department, Royal Berkshire Hospital, for their skilled and sympathetic treatment of the patients we have referred to them.

References

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A young boy with a broken leg was recently admitted to hospital and his younger brother was refused permission to visit as "children are more infectious than adults." Is this true?

This sounds to me like an outdated excuse used by an adult hospital, as distinct from a children's hospital, to discourage visiting of sick children. Presumably someone has failed to recognise that it is eminently desirable for a boy to visit his injured brother in hospital, and for a boy with a broken leg to be visited by his young sibling. I regard the whole thing as a packet of nonsense. It reminds me of a continental general hospital that I saw in which parents were allowed to visit their children in the ordinary children's wards for one hour a week, but they could see them only through a glass partition and were not allowed to enter the ward proper or touch their child—presumably to prevent their children acquiring a dire infection from the parents.

There is no evidence that any particular infection carried by a child is any more infectious than one carried by an adult. It is true that children in their first two or three years at school are apparently more susceptible to colds and sore throats than later, before they have acquired some immunity to them, but adults also get colds and sore throats. Even so, parents' complaints that their child has frequent sore throats are commonly not confirmed by careful observation by a doctor. Paradise *et al*¹ found that only 11 of 65 children said to have frequent recurrent sore throats really did have such throats, and many of these were only mild. Anyway, what harm would it do if a boy with a broken leg caught a cold or sore throat? Would he not be far more likely to catch a more serious infection from one of the doctors, nurses, or other attendants than from his young brother?

¹ Paradise JL, Bluestone CD, Backman RZ, *et al*. History of recurrent sore throat as an indication for tonsillectomy. Predictive limitations of histories that are undocumented. *N Engl J Med* 1978;298:409-13.