Personal Paper

Effects of childhood cancer on long-term survivors and their families

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Summary and conclusions

Problems experienced by families of long-term survivors of acute lymphatic leukaemia and Wilms's tumour were investigated to find out the best way of using limited resources to improve management of such patients. All patients had received treatment at Alder Hey Children's Hospital, and all had completed treatment at least two years before the study. A social worker interviewed the parents of each child. The results showed that various aspects of management needed improvement, including: information given to parents at diagnosis of their child's illness and during subsequent treatment; continuity of care and multidisciplinary teamwork among those caring for the child; greater understanding by school teachers that such children have the same educational needs as others; wider communication by hospital staff with the child's other relatives, particularly grandparents; financial help for parents; and marital counselling.

To help implement these proposals full-time social workers were attached to the hospital. Preliminary results were encouraging, though it is too early to evaluate the long-term effects of the changes.

Introduction

During the past decade advances in the management of children with malignant disease have led, in many cases, to an improved prognosis. Much attention has been paid to the problems of dying children, but little to the problems of children who survive similar conditions. This study was performed to investigate the problems experienced by families of long-term survivors of acute lymphatic leukaemia (ALL) and nephroblastoma (Wilms's tumour) who had been treated at Alder Hey Children's Hospital, Liverpool. It was hoped that the results of the study would indicate how best to use limited resources to improve the management of such patients in the future.

Methods

Twenty-four families were included in the study, 12 of whom had a child with ALL and 12 a child with Wilms's tumour. In each case the condition had been diagnosed at least four years ago, and the child was disease free and had completed treatment at least two years before the study (range two to 13 years). In three of the children's families (one with Wilms's tumour and two with ALL) only one parent took part in the study. The groups were not matched for social class or age at diagnosis. Families of children with leukaemia were not selected, since few patients met the requirements outlined above. Patients with Wilms's tumour were selected for logistic reasons.

Data were gathered from a semi-structured interview and related questionnaire, which were conducted and completed by a social worker with the parents of each child. Though numbers were small, the results of the study showed certain recognisable trends.

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Results

AGE AND SEX OF PATIENTS AND LENGTH OF TREATMENT

Of the six girls and six boys with Wilms's tumour, the condition had been diagnosed in 11 before they reached school age. They had received active treatment for between one and three years and had not been receiving treatment for two and a half to 13 years (mean five and a half years).

In patients with leukaemia the condition had been diagnosed at between three and 11 years, in five before they started school. Only two of the children with leukaemia were boys, reflecting their poorer prognosis. Ten of the patients had been treated according to Medical Research Council ALL trials, receiving active treatment for two or three years. The other two patients had received six and five years' active treatment respectively. Patients with Wilms's tumour remembered less of their earlier trauma, having been younger at the time and surrounded by families who had been offered a better prognosis from the outset. Their parents had somewhat idealised memories of the treatment that their children had received, whereas the parents of children with leukaemia had vivid and apparently accurate memories of unpleasant experiences of treatment, and remained uncertain about the future.

PARENTAL ANXIETY

None of the families believed that their child was cured, so none considered their child to be normal. For most parents anxiety focused on various aspects of the child's development had become part of their everyday life. The parents were asked about their present anxieties and about their reactions at the time of diagnosis of the child's illness. This was measured in terms of the help or treatment sought and received by the parents (table I). Mothers of children in both diagnostic categories experienced, or at least expressed, more anxiety than fathers, but few parents received more than a short-term course of sedatives or sleeping tablets.

It is more difficult to assess parents' anxieties at the time of the study. Each set of parents was asked to rate their combined level of anxiety about the issues listed in table II. The figures do not, however, reflect the expectation of 23 familes that their child was still going to die prematurely because of his disease. This general anxiety hung like a cloud over every family, and some parents had developed rituals that served as protective mechanisms against recurrence of the disease. The other area of concern was whether patients would be able to reach adulthood, marry, and produce normal, healthy offspring. As the

children grew older these issues assumed greater practical relevance to the parents. One girl with leukaemia had already produced a healthy baby. Two other patients were courting seriously. In both cases, the patients' parents had decided to tell the partner about their child's medical history before any official engagement, even though one girl with ALL had not discussed her illness with her parents. Questions about possible impotence did not arise.

PARENTS' MARRIAGES

The parents were asked how the child's illness had affected their marriage. In three families, only one parent was interviewed. In one case the mother had died, and two divorced mothers were seen. Twelve families thought that their marriage had not been affected by the diagnosis, although one of these had always known marital strife, and in another the mother had died tragically after the child's illness had been diagnosed. Six families had been brought closer together. All of these expressed the view that the diagnosis made them re-evaluate their goals and appreciate their family life more.

Of the six marriages that had broken down, four had ended in divorce, one in separation, and one in total lack of communication between husband and wife. In some cases diagnosis of the child's illness put further strain on a difficult relationship. Parents explained the destructive effects of the diagnosis on their marriage as follows: "He refused to acknowledge that she was ever ill." "We both looked to our parents to help us, rather than to each other. This renewed old tensions and difficulties, and we blamed each other for the illness." "He took refuge in alcohol. Eventually he opted out of family life altogether, and his drinking caused financial problems." "After the diagnosis, I only lived for the child. It didn't matter about anyone else." "He just couldn't take the extra responsibility."

RETROSPECTIVE ATTITUDES TO CLINICAL MANAGEMENT

Five families of a child with leukaemia and three of a child with Wilms's tumour said that they were satisfied about management. Two in each category had complaints about chemotherapy. Five families of a child with ALL and eight families of a child with Wilms's tumour had major concerns about radiotherapy and one family of a child with ALL and two families of a child with Wilms's tumour were dissatisfied with their children's individual treatment. Most of the complaints about radiotherapy concerned the fact that the children had to go to another hospital for this treatment, and attitudes, staff, and organisation at the two hospitals differed greatly.

Roughly half the parents in each group thought that they had not received adequate information about their child's illness and its management at the time of diagnosis. Most of the families of a child with Wilms's tumour were completely satisfied with the information that they received from doctors thereafter, while only eight of the families of a child with ALL thought that they had been sufficiently well informed during their child's maintenance treatment, particularly when treatment was withdrawn. Twenty families pointed out how badly they had needed an informed person to talk to who was not a member of the family, especially in the first few weeks after diagnosis.

TABLE I—*Numbers of parents of children with acute lymphatic leukaemia (ALL) and Wilms's tumour who experienced anxiety at diagnosis of their child's condition, and type of help received*

	ALL		Wilms's tumour	
	Father	Mother	Father	Mother
Anxiety caused no concern	0	0	2	0
No help sought or received	9	5	8	4
Short-term drug treatment from GP	2	5	1	7
Long-term drug treatment from GP	1	1	1	1
Counselling (eg from social worker)		1		1
Psychiatric outpatient treatment		1		1
Psychiatric inpatient treatment			1	1

TABLE III—*Problems among siblings in families of children with acute lymphatic leukaemia (ALL) and Wilms's tumour. Figures are numbers of siblings*

Sibling problems	Families of:	
	Patient with ALL	Patient with Wilms's tumour
Feels rejected by parents	1	1
Jealous of patient	4	6
Behavioural problems	1	1
School problems		2
Psychosomatic symptoms		1

PATIENTS' KNOWLEDGE OF DIAGNOSIS

Five of the patients with ALL were said to know the name and, at least in part, the nature of their diagnosis. Three had been told by their hospital doctor and two by their parents. Only three of them ever discussed their illness with their parents. In the other seven families parents were opposed to the diagnosis being discussed with the child. Half of all parents reported that there was no free communication between them and their children about health issues in general.

Three of the patients with Wilms's tumour had been told about the nature of their illness, in each case by their parents. Generally, parents thought that the children had finished their treatment before they were old enough for such discussion to be relevant. The nine uninformed children had been given various explanations for their scars. Only three sets of parents reported any restrictions on free communication between them and their children.

PATIENTS' SCHOOLING

Most of the patients with Wilms's tumour were under school age while receiving treatment, and none of their parents reported problems at school. All these children had satisfied family expectations by their scholastic achievements. By contrast, four parents of children with ALL reported educational problems, not necessarily associated with long absences from, or disruption in, the normal progression through school. Ten children had missed between three and 15 months' schooling. Eight sets of parents reported that primary-school teachers thought that education was not necessary, since the children had no future anyway, and this caused problems for the children when they reached senior school. At the time of the study two patients had left school and found semi-skilled employment. One patient was still having remedial teaching in a normal secondary school.

SIBLINGS

Family structure was examined in relation to sibling needs and problems, using data based on parents' subjective assessments. Four patients were only children. Only one of the others was the youngest child in the family. While four of the patients with Wilms's tumour

TABLE II—*Areas of anxiety among parents of children with acute lymphatic leukaemia (ALL) and Wilms's tumour. Figures are numbers of parents*

	Recurrence of disease	Growth restrictions	Intellectual development	General performance	Ability to form relationships	Marriage prospects	Fertility and sexual potential
			Parents of children with ALL				
Very worried	3				1		
Moderately worried	1				2		3
Little anxiety	7	1		2	1	4	6
No anxiety	1	11	12	10	8	8	3
			Parents of children with Wilms's tumour				
Very worried	3	1					2
Moderately worried	2	1				2	3
Little anxiety	7	2			3	4	1
No anxiety		8	12	12	9	6	6

had younger siblings who had been conceived after their illness had been diagnosed, this applied to only one of the children with ALL. Many parents said that knowledge of their sick child's diagnosis made them decide against further pregnancies.

Five of the families of a child with ALL reported problems with siblings, and in three of them the problems had not been resolved at the time of the study. Parents of children with Wilms's tumour were more aware of problems with siblings, and in five of the seven who reported problems, these were continuing. Table III shows the specific problems mentioned. Many of them began while the mother was living in hospital with the sick child and siblings were boarded out, usually with relatives, and others were due to overindulgence of the patient by adults, especially grandparents.

PARENTS' SOURCES OF HELP AND SUPPORT

The parents were asked who had helped them most. Overall, the answers in each group differed little. Table IV shows the people mentioned, the order of priority being that assessed by the parents.

TABLE IV—*People who had helped parents most, listed in order of priority given by parents. Figures are numbers of families*

Parents of children with ALL		Parents of children with Wilms's tumour	
Primary physician (mainly seen in outpatients)	12	Primary physician (seen mainly when patient was an inpatient)	12
Grandparents	7	Grandparents	10
Outpatient sister	7	Outpatient doctor	7
Neighbours and friends	3	Ward sisters	7
Medical social worker	6	Friends and neighbours	7
Ward doctors	5	General practitioner	4
Ward nurses	5	Other relatives	4
Clergy	5	Medical social worker	2
Other relatives	5	Ward orderly	1
Ward teacher	4	Ward doctors	1
Ward orderly	3		
General practitioner	2		
Health visitor	1		

Clearly, all the parents looked first to the doctor or doctors responsible for their child's treatment, and placed their confidence in them. They thought that continuity was important in the case of senior medical and nursing staff, for as the relationship developed, so the doctors won the trust of the parents and inspired confidence. Relatives were often too scared to be of real help, but understanding grandparents were the second most important source of help, providing both practical and emotional support.

Those families who listed the social worker had usually received financial help from this source. Help from clergy was recognised only by families who had previously attended church regularly. Workmates were an important source of support for fathers, who attributed their better ability to cope to the fact that they could get away from the problems.

FINANCIAL EFFECTS

Seven families of a child with ALL and five of a child with Wilms's tumour, had received financial help during their child's illness, and three claimed that financial problems resulting from the illness were still relatively pressing. The biggest expenses were travelling costs to and from hospital, telephone bills, extra food, heating, and clothing, and special treats and holidays. Charitable funds had a major role in relieving hardship.

Conclusions

Most families reported some difficulties, and this indicates that particular areas of patient management need to be improved. These include the need for: more repetition of information to both parents at the time of diagnosis, and more opportunities to be created for parents to ask questions throughout the period of the family's contact with the hospital; greater awareness by staff of the importance of continuity of care and multidisciplinary teamwork; enlightenment of patients' school teachers, who often think that education is irrelevant to children who have no certain future; hospital staff to encourage greater participation of, and communication with, the extended family, particularly grandparents; financial help to be more readily available; and marital counselling.

PRESENT PRACTICE

By courtesy of the Malcolm Sargent Cancer Fund for Children, full-time social workers have been attached to the Alder Hey haematology and oncology unit for the past three years. This has already resulted in regular staff support meetings, led by a consultant paediatric psychiatrist, evening meetings for parents of children with leukaemia, and more direct contact and liaison between hospital, community health workers, and school staff. Hospital social workers have increased their service to many of the families to cover emotional and practical issues, including marital problems and the constant strains of living with uncertainty. While it is too early to measure the effects of these changes, the results of the study clearly showed that such developments were necessary.

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What is the cancer prevention value of routine cervical smear test, pelvic examination, and breast examinations in young women?

Underlying this question is another one. Does early diagnosis of cancer or pre-cancer, leading to treatment believed to be efficacious, improve prognosis? At first sight the proposition of early diagnosis, early treatment, better prognosis seems unexceptionable, but recently has seemed less certain. It is probably wrong to believe that cancer of any organ is homogeneous. Cancers apparently similar clinically, histologically (including electron microscopy), biochemically, and in other characteristics may behave very differently in individual patients.

Despite a fairly intensive programme of cervical smear taking, the number of deaths from cancer of the cervix have not declined in England and Wales between 1970 and 1976.[1] But in Scotland[2] and British Columbia[3] a decline in death rates seems to have been achieved associated with intensive screening. It is not absolutely sure whether the better results are entirely due to this alone. Pelvic examination has little to offer in the early diagnosis of cancers of the cervix and uterine body. It should detect ovarian swellings, but if these are already cancerous and extending beyond the confines of the tumour the prognosis is poor and has not greatly changed in recent years. Palpation of the breast does not always indicate the extent of a cancer as shown at operation.[4] Early diagnosis then may not improve the prognosis. Deaths from breast cancer have been steadily rising over many years.

Because we do not know how to forecast the biological behaviour of individual cancers and yet some action seems to be necessary there would appear to be little present alternative to attempting early diagnosis except laisser-faire, which will not do. The failures of this policy are spurs to further research into diagnosis, prognosis, and treatment. Acceptance of the simple belief in the value of early diagnosis leads to stagnation. The questioning of that belief should lead to progress; but meantime the simple equation is all we can apply. Recognition that it is not all-embracing is an increase in wisdom and has the merit of reducing therapeutic excesses.

[1] Yule, R, *Lancet*, 1978, **1**, 1031.
[2] Macgregor, J E, and Teper, S, *Lancet*, 1978, **2**, 774.
[3] Boyes, D A, and Worth, A J, in *The Cervix*, eds J A Jordan, and A Singer, p 404. London, Saunders, 1976.
[4] *Lancet*, 1978, **3**, 717.