

Liaison Psychiatry in a Paediatric Oncology Clinic

A decade of experience and change

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Families who have a child with a life-threatening disease need support during the illness¹ and in the bereavement phase.² Although few would disagree, the means to provide such a network is not easy. During 10 years working in an oncology clinic, I have become aware of the importance of close liaison links within the clinic itself and in the community. By the nature of life-threatening and terminal illness, staff members need opportunities to discuss their feelings towards their patients if such extremes as patient avoidance or identification are to be prevented. Once a close team spirit exists, the likelihood of an individual becoming over-stressed diminishes. Although all team personnel are potentially at risk, I would suggest that those at greatest risk are at opposite ends of the hierarchy, i.e. the consultant constantly faced with challenging medical decisions and involvement with emotionally drained parents and the junior nurses, seen as 'safe' people on whom to unburden. The latter spend more time with the families and have no legitimate mode of escape!

For nearly a decade the Cambridge Paediatric Oncology Clinic has run as a liaison clinic. During this time there have been notable changes both within the clinic and in the field of oncology itself. These deserve mention because staff and patients have to adapt to the advances which bring different stress to bear.

Liaison began by case referral to the senior registrar in child psychiatry under consultant supervision. Considerable time was spent discussing such families with the staff; the nurses, in particular, seemed under undue stress. The traditional psychiatric interview seemed of much less value than in out-patient work because of the parents' overwhelming primary need to 'decathect' and because these families were not 'psychiatric' in the true sense but mostly normal families facing an intolerable life stress. The need to understand more about the working of the clinic, the rationale behind treatments and staff coping mechanisms coincided with the paediatricians' wish to discuss the wider implications of childhood cancer, so that true liaison with clinic attendance began in 1978. The aim has been to incorporate parents as team members from the beginning—acknowledging that their central role is in supporting their child. Key workers provide a flexible approach to the families and there is as much continuity of care as possible in the medical, nursing and psychosocial spheres.

In my opinion, the importance of providing a supportive milieu, with the psychiatrist as a team member, provides a crisis prevention approach with formal case referral numbers eventually decreasing as the supportive staff network takes over.

The clinic format

1977

40 Patients

Part-time consultant paediatrician Registrar	
Part-time staff nurse	2 sessions

Nursery nurse	
Ward clerk	
Child psychiatrist	1 session
Hospital social worker	1–2 sessions

1987

120 Patients

(Regional Centre 1986)

Consultant Registrar	7 sessions
Part-time sister	4 sessions
Part-time staff nurse	2 sessions
Ward sister	1–2 sessions
Nursery nurse	
Ward clerk	
Child psychiatrist	1–2 sessions
Malcolm Sargent social worker	6 sessions
Health visitor community liaison	

So far, Cambridge has been lucky as the clinic is manageable on the paediatric ward rather than in more impersonal out-patient quarters. This decreases overall anxiety as the child and his family become familiar with the ward and staff, and continuity of care occurs when they are inpatients.

The first major change was provision of a play room for the oncology patients with regular nursery nurse input. This

allowed the children to separate more easily and become absorbed in play rather than clinging to their parents in a clinical waiting room. The consultant had to work hard for this and eventually a large bathroom was converted! In parallel, the waiting room had a face-lift with the addition of coffee-making facilities, telephone and a more welcoming decor.

Another change was the availability of a parents' group, which met fortnightly for a year. Only a few parents could attend—East Anglia being such a large area—but the spin-off was remarkable. The hitherto chilly waiting-room atmosphere became much more animated and, at the suggestion of this group, more informal education meetings were set up, discussed below. Of those parents who came, generally both parents would attend where possible.

Education meetings have now become a regular event. For parents to help a child with cancer accurate information is vital; more than sympathy³ is needed. With anxiety high at clinic visits, major questions are forgotten. In the informal setting of an evening meeting these sensitive issues can be tackled and myths dispelled. Our format covers talks on:

- (1) cancer—including cell structure and recent advances in research
- (2) drug treatments and interactions—in simple language
- (3) radiotherapy—this topic is shrouded in most concern, not unnaturally when parents have to cope with cranial irradiation.

Attendance varies but around 40 people are usually present. We try to time them when there has been a cluster of new families, who have had time to attempt to digest the illness and its ramifications. It has the invaluable secondary gain of introducing families from the two different clinic days.

It is usual for erroneous ideas to be explored in the safety of the meeting, e.g. do changes in the body occur every seven years? Can cancer be cured by a protein-free diet? Increased staff support has occurred in three main ways:

- (1) a core of stable personnel, with considerable experience aids the transition for new staff members
- (2) nurse discussion groups
- (3) psycho-social meetings.

Nurse discussion groups were set up to discuss a ward family who were causing havoc and polarity in the staff. The main theme was the aggression stemming from the father of a terminally ill child. Everyone worked hard and the outcome for the family and the ward was a lasting improvement.

The main purpose of the meetings is to allow staff to reflect in more depth about certain families away from ward demands, and to pool resources. Another function is that it provides an additional communication bridge between the ward and clinic staff, helping to prevent a 'them and us' situation. Problems often encountered are the plight of the

dying adolescent and the prolonged terminal phase or unexpected death of a child, when everyone feels drained and impotent.

I have found the rigid psychotherapeutic approach has to be tempered. Sometimes, it is difficult for staff to be on time and sometimes they do not want to talk about problems, and that is their right. Unlike usual group situations, one has to cope with the shift system and thus a changing membership. Nevertheless, when a universal problem arises attendance is good and night nurses may make the time to come during their off duty.

Student nurses are potentially at risk. While on the ward they are given grounding in medical oncology and offered two sessions to discuss the importance of family dynamics in childhood illness.

The psycho-social meeting is held on a fortnightly basis to discuss families causing concern, and to review families at critical phases in the disease, e.g. in relapse or terminal. Its most important function is its 'presence' so that there is a designated time when all key team members can meet together.

The advent of the Malcolm Sargent social worker was in 1981. Most oncology clinics are now helped by this source and their contribution is immeasurable. Our clinic has grown from 40 to 120+ patients during the past decade, due to improved cure rates and because it is now a designated regional centre. The role is to support families with children under 21, ranging from practical and financial aid to long-term availability and counselling. It would be impossible to make lasting impact without this valuable resource.

During the past decade there have been major advances in the treatment of childhood cancer. For most disorders a combined chemotherapy and radiotherapy programme is designed. For acute lymphoblastic leukaemia survival is now 60–80%, with rates for Wilms Tumours and Hodgkin's disease much higher. Thus the scales have tipped in favour of long-term survival rather than mortality. There is a shift in parental expectations and coping mechanisms. Families are faced with prolonged uncertainty and it can be more of a blow when relapse occurs.

Bone marrow transplantation is now available for some poor prognosis cases and, although a miracle when it works, there is a mortality from the actual process and unpleasant deaths do occur as the child's own marrow is obliterated before transplant occurs. The stress on siblings or other family members if they are incompatible or compatible and their relative dies needs evaluation, but either way the stakes are high.

With the improved facilities for terminal care at home, more children are now dying there. In our clinic over 80% of children will die at home. Liaison links such as paediatric district nurses and the Malcolm Sargent social workers have helped bridge the hospital community divide. There is improved pain control and the advent of a small pump

which can administer continuous analgesia has expedited this further.

The future

Although every effort is made to provide on going support for bereaved families this is not sufficiently comprehensive due to lack of resources. Families are encouraged to return between three and five months to see the paediatrician and to go over their child's illness in detail. During this time a member of staff will have kept in contact. I would like to see a more definitive supportive network for the community workers. Often health visitors and district nurses are willing to support families but through lack of support for themselves, their involvement dwindles. The bereavement phase after child loss is long,^{1,4} the second year often being as difficult as the first, because support is withdrawn while families are still adjusting.

The concern for siblings needs further practical thought. Could school nurses or school tutors become key supports for bereaved siblings? Sensitive brothers and sisters do not add to the burden of their parents and may become withdrawn and suffer in silence.

Adolescent cancer sufferers pose a special problem. Paediatricians are more geared to considering the whole family than their adult counterparts, but being a solitary adolescent with a group of seven year olds can be demoralising. We are currently trying to provide a special room for adolescents but on a cramped ward this may not be feasible.

A counselling course for team members, especially nursing staff, is needed to consolidate their knowledge and is being organised in conjunction with our child development clinic.

Despite the threefold increase in patients the psychiatric input has remained relatively constant. This is largely because of the staff's realisation and acceptance of the normality of particular phases of grief, notably anger, sadness and bargaining which are related to diagnosis, relapse and the terminal phase. Although my role is now concentrated on supervision, education and support, I carry a small care load and assess families who are finding adjustment difficult.

The psychiatric presentations vary enormously, from one father threatening to hang himself if his child died to a grossly regressed 12 year old whose sister had died. Only once has psychiatric admission been required. This was a woman of borderline intelligence, overwhelmed by anxiety when her child relapsed and became incoherent and inaccessible. However, she later coped well with her child's death and underwent a normal grief reaction. Needle phobia has not been a major problem but one of our clinical psychologists has proved helpful with this. Most interventions are less dramatic and can be resolved with a few sessions—mostly family interviews where there is stress related to a particular issue, e.g. forthcoming amputation or adverse reaction to chemotherapy or with parental discussions in the terminal phase. Although the ethos of the clinic is openness, many parents still opt to withhold explicit knowledge that their child is dying. We now know that most children above the age of seven or eight would have gleaned this knowledge anyway.⁵

Although individual counselling for all dying children might prove helpful, it is essential that the dying adolescent has access to someone outside the family to discuss their fears and sadness. Adolescents often protect their families and put on a false front and maintain mutual pretence throughout their terminal phase.

Many models of liaison exist but for childhood cancer a therapeutic milieu with a cohesive multi-disciplinary team seems to offer the best chance of prevention and early detection of stress. I hope this paper has shown that mutual collaboration does have a potentiating effect and is more valuable than the sum of the individual parts. I also hope that in medical circles thought will be given to the optimum size of oncology clinics as harrassed, overstretched staff cannot be expected to provide the calm therapeutic atmosphere necessary for total patient care.

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