EDITORIAL

Amy and David, writing in this issue, have much to teach us about how it feels to be a youngster with cancer, how it feels to be the brother of someone with cancer and how it feels to lose your friend from the same disease that you have. For many counsellors and nurses, finding the right words to say to children who are suffering is so daunting, that they funk it. And yet children are acute observers, and when they also have the ability to express what they see and feel, we have to listen. Margaret Andrews, a social worker, felt inadequately trained and experienced when she was asked to take three Vietnamese children to see their mother's dead body—she would have funked it if she could, but a strong sense of duty drove her and she found, to her surprise, how healing it was for her charges and how rewarding, too, for her.

We publish, too, accounts of practice in Denmark and in Greece. In Greece, tragically, children were infected with AIDS through transfusions of blood to treat their haemophilia and thalassaemia. Tsiantis and Meyer have given us a very practical account of their work with young people and their families facing illness and death, which should be helpful to all those struggling with these issues in other countries too. Grief, as we learn, is a universal experience for humans and higher animals. Ms Hansen works with obstetricians to help parents who lose their baby and has presented us with a structured approach to the task which combines attention to mind and body. The work needs evaluation, in due course. In this country many centres are offering similar programmes and we would like to hear from readers in other countries about their practices with this vulnerable group.

Editor

Counselling HIV-Positive Young People with Thalassaemia and Haemophilia and their Families

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In this paper we present our experience and observations from work with multi-transfused children, adolescents and young adults who are HIV antibody-positive and with their families. In some cases, these patients display the symptoms of the disease from which they are dying. We shall focus on the issues which have to be considered in dealing with and counselling these patients and their families, with an emphasis on the question of bereavement care.

These multi-transfused patients have β-thalassaemia or haemophilia and are treated at the following clinics of the Aghia Sophia Children's Hospital in Athens, Greece; the Thalassaemia Unit of the Department of Paediatrics, Athens University Medical School (10 patients aged between eight and 23 years); and the Haemophilia Department of the same hospital (20 patients aged between seven and 21 years). The psychosocial intervention programme was implemented by an interdisciplinary team from the Aghia Sophia Children's Hospital, and its objectives were to help parents and other family members contain the anxiety of antibody-positive children and improve the interaction and communication within the family, between the family and their health carers, and between the family and the community.

Psychological Impact of AIDS

The AIDS epidemic has caused great concern, and even panic, in public health services and throughout the world, and the disease has come to be described as the plague of our age. Many of the campaigns undertaken by the health services in various parts of the world have attempted to address issues related to the control of the disease and prevention of new cases.

On the other hand, systematic efforts have also begun to investigate the psychological impact on AIDS patients and carriers and their relatives. In many of these cases, AIDS patients and their families go through phases of social isolation, stigmatisation, feelings of futility and mourning reactions. Nichols[1] observes that among the stress factors which occur as a result of the disease is the fear that the disease may be passed onto others. This may cause particular problems for the healthy members of the family, who may react by avoiding the patient as a way of self-protection. Ambivalence becomes pervasive in that the traditional value of family responsibility for the patient's care and support is jeopardised, creating a new undercurrent of family stress and adding to the precariousness of the new situation. Discord among family members can ensue over the question of confidentiality, since no common consensus on the scope of information-sharing can be readily achieved on an objective level[2]. Bereavement is often exacerbated for the parents of patients who had previously envisaged the survival of their offspring. The behaviour mode is the result of the pre-diagnosis relations, previous grief experiences and overall adaptability to periods of incipient radical change[2].

HIV multi-transfused patients

In the case of multi-transfused patients—who are usually patients with thalassaemia or haemophilia —the following factors should be taken into consideration in counselling work. Thalassaemia patients are affected by a serious chronic form of haemolytic anaemia which requires frequent (every two to three weeks) transfusions of blood if the patients are to survive. The disease is inherited from both parents, who are carriers. Children, adolescents and young adults who have thalassaemia display a range of emotional, behavioural and social problems. They tend to be dependent on their parents and they may display social isolation; especially in those cases in which their physical development is affected and they fail to reach an average height, the secondary sexual characteristics do not appear at the normal time, or there are abnormalities in their facial or bodily appearance. The parents of thalassaemic patients have been described as overprotective. It has been suggested that this overprotectiveness may be linked to the guilt feelings experienced by the parents as a result of the fact that they passed the disease on to their children[3, 4].

Haemophilia is an inherited condition which mothers pass on to their sons. The symptoms of the disease take the form of internal haemorrhage, usually in the large muscle groups and the joints. The problems which haemophilia may cause in these children are familiar from the literature: fear of injury and risk-taking behaviour; dependence on parents; etc. The parents of haemophiliac patients have also been described as overprotective[5, 6, 7]. In haemophilia, the haemorrhage problem is managed by administering the factors required to stop the bleeding.

In both thalassaemia and haemophilia, the administration of blood in the form of transfusions or blood products was the way in which, before 1985, the patients in our study became infected with the HIV virus. Screening of donated blood and the heat treatment of blood products has all but eliminated the risk of new infections with HIV.

In the case of multi-transfused patients, infection with HIV virus occurs against a background of chronic disease. As a result, the family suffers a combination of stresses: old traumas and conflicts resurface, while a new set of mourning reactions are created by the second, fatal diagnosis, that of the HIV virus infection, and the resulting threat of loss or the loss itself. This second diagnosis is truly catastrophic for the family because the patient has become infected through transfusion or injection of contaminated blood products. These procedures were an integral part of the required treatment, and at the time neither the doctors nor the patients' families were aware of the associated risks.

Reactions on diagnosis

In general, the reactions of parents, adolescents and young adults to whom the diagnosis was disclosed were as follows:

1. Period of crisis

The parents reacted with shock, grief, guilt and anger directed towards the medical and nursing staff, whom they held responsible for infection with the virus. The adolescents and young adults reacted with anxiety, depression and a desire to find out as much as possible about what had happened to them. A very small number of patients reacted with aggressiveness and acting-out behaviour. In general, there was a state of crisis which, after the first few days, passed into the next phase.

2. Aysmptomatic antibody-positivity phase

During this period, we observed that the families became socially isolated in attempting to cope. The parents used all the familiar ways of dealing with the chronic disease, relying on their previous experience of it. At the same time, they became overprotective towards their antibody-positive children and adolescents.

The tendency for social isolation arose out of fear that friends, relatives and the social network would discover the truth and reject them. Another fear was that they would not be believed when they said that infection with the virus had occurred because of transfusions or the administration of blood products, but that it would be attributed to unacceptable and prohibited sexual behaviour, or the use of narcotics. Almost all the parents reacted negatively to the possibility of discussing with their children the infection with the HIV virus. This attitude seems to have been dictated by the following factors:

- A logical decision not to talk to the children: why burden them with an additional problem? What would be gained from telling them?
- The defence mechanism of denial, ie of not accepting that the child had the disease, proved to be predominant.
- As a result, a conspiracy of silence developed within the family, in which everyone seemed to know that something terrible had happened but did not discuss it with each other. Maintaining this cover-up consumed a considerable amount of mental energy and increased family tensions[9].

3. Complications, symptoms and the final stages

In this phase complications occur, the patients are frequently hospitalised, their physical condition deteriorates and death approaches. The parents are often mentally fatigued and distressed. The marital relationship may be affected, and the parents frequently neglect the needs of the healthy siblings. The parents once again have to face the problem of making a disclosure, not only to the sick children but also to the healthy siblings and the other members of the extended family. The family lifestyle is also profoundly affected by the following factors:

- An alteration in parental roles: the mothers spent nearly all day at the hospital, and the fathers had to devote more time to work.
- Financial problems.
- Emotional stress.

Once more, the families are called upon to test out their strength in dealing with the new crisis. At the same time, they have to abandon all hope of the survival of their children.

Adolescents and young adults

In the case of adolescents and young adults, the following factors need to be taken into consideration.

Adolescents and young adults who are under the stress of the disease will tend to regress, to display behavioural difficulties and to be unwilling to co-operate with treatment. Regression and acting-out behaviour are in any case features of adolescence, and the anxiety and panic caused in these young people by the threat of being antibody-positive or of having the disease of AIDS will intensify such behaviour.

Studies of adolescents and AIDS have shown that they are increasingly more aware of the ways in which AIDS is transmitted and of how it can be prevented. However, the correlations between levels of adolescent knowledge and attitudes, on the one hand, and their behaviour, on the other, are low: in other words, knowledge and awareness on the part of the adolescents about the ways in which AIDS is transmitted and how it can be prevented, have little effect on their behaviour.

The death of adolescents or young adults is particularly difficult to accept, since the attitudes and beliefs of society are that the lives of adolescents and young people

will continue, whereas older people are recognised to be more vulnerable to illness and death. Thus reactions to the fatal disease are much more intense. The peer group finds the prospect of death difficult to accept, while the parents often experience the imminent death of their child as a punishment.

A case study

Using these comments as a basis, we should like to focus on the case of Dennis, which highlights the different phases in Dennis's responses and how these responses were managed by the second of the authors as Dennis began to learn the impact of HIV diagnosis.

Dennis was a 19-year-old technical school graduate employed as a mechanic. He had been diagnosed as suffering from thalassaemia at the age of seven months, and was attending the clinic for blood transfusions every three weeks. Dennis and his younger brother were raised by their maternal grandmother: his mother, long plagued by health problems, died of cancer when he was 11 years old. His father, although living in the household and sharing the expenses, was seen as emotionally distant. The counsellor had been working with the patient for slightly over a year when the HIV diagnosis was disclosed to him. His grandmother was adamant that Dennis should not be told of the diagnosis, because she was afraid that he would be unable to handle it. She prevailed upon the staff to withhold the findings from him, and even went to the Chairman of the Hospital's Board of Management in search of assurance that the secret would be kept from him. We continuously tried to engage this strong-willed woman in order to allay her fears, striving to clarify the much deeper issues about Dennis's needs and strengths. Team liaison was necessary.

Suddenly Dennis's T4 cell count dropped, a sign that his resistance to infection was reduced. At this point, treatment with AZT was introduced, a drug which inhibits the progress of the disease. The physician now needed to tell the family about the HIV infection. The grandmother felt under great stress. The counsellor continued to support her, pointing out how effectively Dennis had handled crisis up to that point. The focus of counselling work with Dennis was on the 'triple-S' strategy: Self-esteem; Self-control; Strength in coping. He was also helped to deal with hospital staff, using an approach which maximised his understanding and effectiveness.

Much of the conversation between Dennis and the counsellor concentrated on his work and his hobby, motorcycles. He evidently possessed an encyclopaedic knowledge of this subject and enjoyed the opportunity to share it. This became a method of strengthening his self-esteem; the counsellor's responses took the form of enthusiastic listening and encouragement, thus inducing gradual bonding and trust. When Dennis spoke of his employer's respect for him, the counsellor served to validate this.

Dennis was quite forthright in expressing his frustration with the staff: he said they made him feel weak, ill-informed and unable to make his own decisions. He apparently felt misunderstood, if not infantilised to some extent. The counsellor tried to reassure him that the staff really cared about him, but might be abrupt or fail to sense fully what he needed to hear about in depth. She then explored with Dennis mechanisms which would enable him to gain better control over the outcome of the situation.

Following disclosure of his HIV-positivity, Dennis confronted the counsellor in depression and anger: 'So you were in on it too!' After a silence, the counsellor admitted that he was right, and asked him to share his feelings. Dennis talked about what the diagnosis meant for his life, and how he felt both furious and disappointed. The counsellor discussed with Dennis the reasons for the delay in disclosing his condition, and validated his candour and his right to be angry, hurt and shocked. For a while Dennis then retreated into a 'nothing has changed' denial stance, which lasted for the next few sessions. Preventing loss of weight became a key concern.

Sex-related issues soon came to the surface. The need to make use of contraceptives for preventive purposes caused problems. He had lost the freedom of his former spontaneity, which spilled over into attitudes to, and his mythology of, relationships. The fact that he had recently purchased a car, thus giving him the mobility to go out with girls, contrasted with the sense of deprivation caused by the HIV diagnosis. In the meantime, we emphasised the positive factors: his circle of friends and his newfound mobility. However, the uphill fight he had been experiencing since childhood was now being repeated, and he had to marshal the abilities which he had already proved himself to possess for the new challenge ahead.

In retrospect, the dilemma of becoming engulfed in intra-family struggles raises the question of how much to disclose to whom. There are no infallible rules to ensure that the best interests of the patient, and those who take care of him, always coincide[10, 11].

When a chronic condition like thalassaemia is interposed with an acute and lethal disease such as AIDS, spontaneous combustion of the entire system of emotions is likely to occur. The situation is tinged with trauma for patients and their families, and there are also abundant opportunities for the counsellor or mental health professional to be faced with ethical and therapeutic dilemmas.

Counselling procedures

In general, the procedures described below for psychosocial intervention and counselling work were followed in managing the antibody-positive children, adolescents and young adults. The intervention was conducted by an interdisciplinary mental health team consisting of a child psychiatrist, a psychiatric social worker and a clinical psychologist[8].

The crisis period

Our intervention to cope with the stage of diagnosis of antibody-positivity, which was usually accompanied by crisis, took the form of crisis intervention and included the following features:

- Provision of information about the significance of HIV-positivity, the illness itself, treatment, the way in which the virus is transmitted, etc. In other words, assistance of an 'educational' nature which was designed to help the family gain control of the situation.
- Encouragement to express painful feelings and emotions stemming from the situation.
- Provision of reassurance that the family's strong reactions were not abnormal, but were part of an adaptive process.

In general, the objectives of work with the parents at this level were:

- *allieviation of stress*
- problem management
- holding.

Period of asymptomatic antibody-positivity

Intervention at this stage consisted of:

Assisting the parents to:

- prioritise their needs
- gain a better understanding of what had happened
- free themselves of irrational guilt and realise that the illness was not an unfair punishment
- facilitate the mourning process
- strengthen their defences
- maintain daily functions and routines.

Advise the parents over their attitudes:

- to the child
- to each other
- towards the social environment.

The intervention included:

- Opening up channels of communication among the members of the family.
- The offer of specific help to cope with the question of whether or not the parents would tell anyone, and if so, whom. More specifically, help in skill building and in talking to children, with information about AIDS so as to facilitate parent-child communication on issues related to AIDS.
- Encouraging the family to develop and maintain links with the extended family and local community agencies and to make use of mental health, social and community services. The family was also advised to avoid unnecessary publicity, which might arouse discrimination and hostility.

In general, work concentrated not so much on issues of loss and death, as was the case in the previous stage, but primarily on issues of quality of life and life-affirming support, respecting the mechanisms of adaptive denial.

Complications, symptoms and the final stages

During this stage, a new crisis occurs. Parents and other members of the family display intense anxiety, coupled with despair at seeing their hopes shattered. The imminent death hangs over the family. This is a period when special needs have to be met: some patients may require hospitalisation, while others can be cared for at home with additional help

Our intervention consisted of:

- Help in coping with grief reactions and facilitation of mourning processes.
- Help in dealing with the siblings of the sick child and in preparing them for the imminent death.
- Help with the special needs which may have to be met.
- Help in keeping open lines of communication amongst the members of the family and with the health care staff.

This last point is of the greatest importance, because the staff's relationship with the parents is quite seriously affected. This stems from the fact that infection with the HIV virus is iatrogenic, since the caring staff have contributed to its transmission through the blood transfusions. The blood or blood factors, which once gave life, have now given death. As a result, the staff are sometimes unable to maintain boundaries in their relations with the parents and the children. On the other hand, the parents feel angry and aggressive towards the staff and their trust in them is shaken.

Our intervention and counselling on this level has been very useful and has acted in a catalytic manner. The team is the liaison between the family and the staff who care for the sick children and their families.

Adolescents and young adults

Adolescents require particular assistance with the developmental issues which have been affected by their disease and its treatment, such as peer relationships; school and academic functioning; normal play; dating and sexuality (including choices of sexual activity and its frequency, and attitudes towards the use of prophylactics).

The general attitude of the family and of the parents towards issues of sexuality is also of importance. More individualised help is recommended for adolescents, according to their needs, age and social class. Such help should be provided by experienced mental health clinicians.

However, since the gap between the adolescents and the clinicians is often quite wide over such issues, it would frequently be advisable for the counselling to be conducted by a suitable person to whom the adolescent feels close, for example a counsellor from the community in which the adolescent lives.

We shall conclude this brief presentation with a summary of some guidelines for managing the families of adolescents and young adults.

Families

Assess the psychosocial background. Encourage parents to avoid secrecy and blocking of communication among members of the family. Persuade parents to talk to their children about infection with the virus at an age-appropriate level. Search for supportive resources within the family system. Help the family to avoid withdrawal and social isolation. Stress the importance of maintaining family routine and caring about coping with everyday problems. Place emphasis on the importance of a mutually supportive marital relationship. Offer opportunities for individual or family counselling as well as parents' and self-help groups. Advise families to avoid unnecessary publicity, which may arouse discrimination and hostility (see fig. 1).

Figure 1—Guidelines for counselling families

Stress the importance of the marital relationship.

Keep up family routine.

Identify and use psychosocial support resources in family and community.

Encourage sharing of experiences in parents' or self-help groups.

Avoid secrecy about the virus in the family.

Avoid social isolation.

Avoid unnecessary publicity.

Offer knowledge on issues related to AIDS transmission, safety precautions and known treatment methods.

Help facilitate mourning processes, when appropriate.

Children and adolescents

Help parents contain the anxiety of antibody-positive children and their siblings. Advise them strongly to avoid overprotection, showing preference to the antibody-positive child or neglecting his or her siblings. Emphasise the necessity for the antibody-positive child to communicate and maintain contact with the peer group. Make sure that children and parents know that the counsellor and their physician will help them all the way through (see fig. 2).

Figure 2—Guidelines for counselling adolescents and young adults

Talk about the virus on an age-appropriate level.

Encourage children to talk about their fears and anxieties.

Meet emotional needs without fostering regression.

Avoid overprotection and discrimination towards the children.

Relieve and contain the children's anxiety.

Encourage children to maintain their bonds with the peer group.

Conclusions

HIV infection in thalassaemic and haemophiliac patients creates the following tensions within the family: fear of infection; fear of death and dying; anxiety about whether—and how—to tell the patient that he or she is HIV-positive or has the disease. The family may be socially isolated. Special skills are required on the part of carers in each successive phase. Initially, crisis intervention work is needed immediately following diagnosis. Next, help is required to prioritise needs, facilitate communication within the family and encourage individual members to express their grief.

Subsequently, help is needed to strengthen coping skills and facilitate family adjustment. In the termi-

nal stage, families need to be enabled to utilise community resources and to cope with the new crisis, while at the same time the patients' special needs have to be met. Counselling must address the special needs of the patients and their families, taking into account such factors as age, developmental stage and inner resources.

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Loss

by Amy Shindler, aged 14

Quite recently I have lost someone that I didn't know very well but, in a way, knew better than her family and closest friends. We first met two years ago, in November 1987. I don't have a very good recollection of my life at that time, because most of it is a medicated blur, but I do remember first meeting Beth. She was ten at that time, and I was going on 13. I met her as I was being led briskly through the rabbit warren of bleak hospital corridors trying to keep the scurrying white nurse in view.

Beth was fairly small with long blond hair and I sensed a feeling of being lost, powerless and very frightened about her. I felt angry with her and it is only now that I realise why: I was feeling exactly the same. We were both there for a bone marrow test, because we were both very ill.

Seven weeks before that time I had been at home for ten days with a high temperature and the 'flu' and as soon as I was well, I went back to school. There was the school play of 'Animal Farm' which I was in, and there was a lot of mad rehearsing before the performance, a couple of weeks later. Throughout all that time I was suffering from very painful headaches and migraines, and I began to go blind in my left eye. Naturally I thought this due to the loss of my reading glasses when I had the 'flu', until my left eye stopped moving to the left.

I remember the performances of 'Animal Farm' as a lot of scenes in between which I would race upstairs to fend off the headaches with more paracetamol. I also remember how ironic it was that at the end of the play I had a line 'I think I must be blind, I cannot see the wall any longer' and I really couldn't see the wall any more. So a week later came the fateful Wednesday, the night of the Kings Cross fire and the night and early morning of my hospital visitations. I went to the optician after school who sent me to my GP, who sent me to Moorfields Eye Hospital, who sent me to the National Hospital for Nervous Diseases.

That was one of the most frightening nights of my life, when I was put in the Intensive Care Unit, surrounded by insane, bald and bony women hooked up to life support machines. Basically what happened next was that I was told they had to operate on me, before I went blind in my left eye. They told me at one point, (although my mum does not remember this) that they would have to remove my eye altogether. But they decided to go in through the skull and risk touching the brain.

However because of my stubbornness and much to everyone's surprise, I got myself out of that hospital 10 days later and about three weeks after that, I was brought to the Royal Marsden in Sutton, where I met Beth. It was here that I was told that they had removed a cancerous tumour from behind my eye and I would need chemotherapy and radiotherapy, to make sure the cancer had not spread anywhere. So my first test was a bone marrow sample.

Beth's cancer was exactly the same as mine, a 'rhabdomyosarcoma', but in her arm, a higher risk area. This meant she must undergo more intensive treatment than me. I began to see her more around the hospital and as our mums became friendly, so did we. Our main topic of conversation was the chemotherapy and I should explain about this.

Chemotherapy is the process of flowing poisonous drugs through the system to kill the bad cancerous cells. However, in some people this also kills the stomach cells, making them vomit a lot. I was one of those people. Beth was not. I was sick every three minutes for five hours and Beth's chemotherapy had no effect. This seemed terribly unfair to me. But then we had something else in common; we were both losing all our hair, caused by the chemo. I wore berets and Beth wore a wig.

Then they intensified Beth's treatment and the next time I saw her, she seemed very white and small and frail. She had a Hickman line put in. This is a tube put in the chest so that the drugs go straight to the heart instead of being drained through a needle for an hour and a half like I had. I wanted a Hickman line too: I hated that needle and I'd often retch as I watched the vile yellow chemo drug drain through the needle into my blood stream. My stomach churns as I write this two years after.

A couple of months into the chemo treatment, Beth went in for her dose before me, she had a Hickman line because her drugs were more intense than mine. I remember hearing a wail from her treatment room and I knew my