

Health Systems

Edward G. Kasili

Coping with cancer in sub-Saharan Africa

With mortality rates from cancer in sub-Saharan Africa approaching those in developed countries, there is clearly a need for improved methods of treatment, especially chemotherapy. But there are many obstacles in the way, ranging from the fatalistic belief that all cancer is incurable to critical shortages of trained personnel, facilities, and drugs. The author proposes an orderly programme for overcoming these problems.

About two decades ago, it was widely believed that malignant neoplastic disease was rare among Africans. However, the introduction of cancer registries in many centres and the progressive documentation of cases has shown this belief to be wrong. For instance, cancer deaths in Kenya account for as much as 20% of the overall mortality in adults and 9% of that in children. The situation is likely to be much the same in other countries of sub-Saharan Africa and comparable to that in Europe.

Malignancy, as seen in Africa, generally strikes younger age groups than in Western countries and kills rapidly. This has far-reaching implications for the economically productive population of the developing countries and for their economies in general. However, these facts are understood neither by the lay public nor by health planners who thus do not take them into account in their health budgets. Inadequate finance magnifies the considerable problems already confronting cancer workers

in sub-Saharan Africa and makes the measurement of the extent and nature of the cancer problem a matter of priority. At present, we rely on hospital-based statistics, which are obviously inadequate. Similarly, efforts to control cancer morbidity and mortality must be based on knowledge of their etiology. Such information is available only for Burkitt's lymphoma and possibly for primary hepatocarcinoma, carcinoma of the nasopharynx, and carcinoma of the oesophagus.

The Nature of the Problem

A rational approach to cancer therapy is only now beginning to be possible in most African countries. Until the late 1960s, the sole treatment was surgery. Radiotherapy, which has been in use for over 50 years in Europe, is available in only a few centres in Africa. Chemotherapy was first used in Uganda in the mid 1960s, e.g., cyclophosphamide for Burkitt's tumour and nitrogen mustard trials for Kaposi's sarcoma.

On presenting themselves for treatment, the majority of patients already have advanced disease with large tumour burdens. These will obviously have a relatively high proportion of

The author is Associate Professor of Haematology at the University of Nairobi Medical School and Honorary Consultant Haematologist at the Kenyatta National Hospital, both in Nairobi, Kenya.

drug-resistant tumour cells which are a source of tumour recurrence when the susceptible cells are killed. Even when patients are seen at an early stage at peripheral hospitals, diagnostic services are often centralized and confirmation of the diagnosis is delayed, with the result that chemotherapy is begun too late. This adversely affects the initial response of the tumour to therapy and causes high failure rates, brief remissions, and short survival. This is particularly true of leukaemia patients in Kenya, the majority of whom die before therapy is even started.

Another problem is that, owing to inadequate facilities, staging procedures are often of limited scope; this leads to understaging of the disease in most cases, which in turn affects decisions about the type of treatment and the eventual prognosis. The chemotherapist thus frequently finds himself consulted only as a last resort. The primary physician's lack of interest in chemotherapy, compounded by a fatalistic view that all cancer is incurable, not uncommonly leads to the inappropriate channelling of patients, causing further delay. This negative attitude is enhanced by uncertainty about the rationale and principles of cancer management and denies the patient the benefits of treatment.

The shortage of oncologists and chemotherapy-oriented physicians and the overworked and overcrowded centres result in sub-

In Africa, Western-developed drug protocols are often ineffective; increased dosages and more vigorous regimens are frequently needed to obtain comparable levels of remission.

standard care, even when treatment is available. The lack of the meticulous approach required in the management of cancer patients contributes to increased iatrogenic complications. Psychosocial aspects, which are of increasing importance in the total care of cancer patients, are rarely given any attention.

Apart from scattered data on cancer in Africans in general, there is hardly any information

on the biological evolution of the majority of cancers. For example, such tumour characteristics as cell kinetics, doubling times, and the presence of cell markers, needed for the design of effective chemotherapy protocols and for prognosis, have not been studied. Chemotherapy in our patients therefore remains a question of trial and error, since the available data on the effectiveness of drugs, which were collected in studies on Caucasians, do not necessarily apply to African patients. This is borne out by our experience in Kenya, where standard protocols for inducing remission of acute leukaemia in Caucasians are not as effective in Africans. In fact, the dosages have to be increased and more vigorous regimens used before similar results can be obtained.

Turning to logistic problems, cancer chemotherapy is more difficult to handle in sub-Saharan Africa than in Europe or America, because the service is usually limited to one centre, either for the whole country or a large catchment area, often at a considerable distance from the majority of patients who thus do not come for treatment. Or if they do, their tumours are already too advanced for them to benefit from treatment. Even for those who do achieve some form of remission, follow-up and maintenance therapy are often abysmal failures.

These problems are complicated by the fact that cancer is new to the African concept of disease, and many patients seek medical attention only when they are totally incapacitated, especially when the neoplasm is painless at the beginning. Such patients tend to rely initially on quack doctors and only turn up at hospital when they are unfit for any aggressive treatment. Furthermore, this lack of understanding makes patients resist surgical procedures that could cure them in the early stages of their disease. Indeed such patients, once they get symptomatic relief, default because they do not understand the need for continued drug treatment or frequent clinic attendances. Also they generally do not take the oral medication as instructed, making intravenous therapy mandatory. Where successful follow-up treatment would be possible, supervision from the primary care doctor is either lacking or inadequate, even when guidance from an experienced chemotherapist is available.

Chronically inadequate supporting services severely jeopardize the success of chemotherapy. For example, component haemotherapy, tailored to support cancer management, is frequently lacking at both peripheral hospitals and referral centres. In addition, such factors as inadequate laboratory facilities, shortage of antimicrobial agents and an aversion to interdisciplinary teamwork contribute to making cancer chemotherapy a very difficult, frustrating and often unrewarding endeavour. Moreover the nursing staff do not have the necessary experience to care for the very ill cancer patients.

Despite the high cost of cancer, in both direct and indirect terms, the question arises whether it is worth while to spend large sums on expensive cancer drugs rather than use such resources on the more preventable causes of ill-health in the community. This problem is clearly felt in the developing countries of sub-Saharan Africa where foreign exchange is often in short supply. One side-effect is a chronic shortage of antineoplastic drugs either because their cost is prohibitive or because they have been relegated to a position of secondary importance in essential drugs lists. Consequently, effective long-term therapeutic regimes cannot be sustained and alternative regimes in resistant cases are virtually non-existent. This adversely affects not only the quality of survival but also the rates of remission.

Another problem, not directly related to cancer chemotherapy but deriving from it, is the complete lack of facilities for the physical and psychosocial rehabilitation of the long-term survivors. Although the few chemotherapists in Africa have yet to encounter this problem, it should be anticipated for the near future. This aspect is little understood and the uncertainty about the outcome and side-effects of therapy is not usually discussed with the patient or his relatives.

What Can Be Done?

In view of these problems, it is inevitable that the results of cancer chemotherapy in sub-Saharan Africa will be inferior to those obtained in Europe and America. Treatment failures are frequent, remission rates are low, and the quality of patient care and survival pros-

pects are poor. The majority of the patients are given only palliative treatment. Should we accept this as a transitional stage in the development of cancer chemotherapy in Africa? It need not be accepted if active steps along the following lines are taken.

Centralized treatment

At this early developmental stage of cancer chemotherapy in sub-Saharan Africa, the approach should be that of centralization in spite of the problems of follow-up discussed above. The existing centres should be strengthened and made responsible for training the medical

Cancer is new to the African concept of disease; patients thus tend to ignore painless neoplasms and seek medical attention only when they are totally incapacitated.

and paramedical personnel needed to open other centres. It is only at these centres that a multidisciplinary approach is feasible, which alone will permit an improvement in therapeutic results. These centres would supervise research and surveys of the incidence, prevalence and patterns of cancer.

Training in oncology

Medical oncology, as a discipline, should be integrated into medical school curricula, at both undergraduate and postgraduate levels. All teaching hospitals should establish cancer treatment units under teams of physicians specially trained in various aspects of oncology and drawing on the general expertise of the hospitals. The policy and practice of integrated teamwork should be inculcated into the prospective oncologist from the outset, and all doctors should be trained to accept the fact that a cancer patient is no different from any other patient either medically or ethically, and is entitled to the same quality of medical care. Besides minimizing the fatalistic attitude towards cancer, this will contribute to early diagnosis and an awareness that cancer must be treated urgently.

National cancer planning

It is vital for governments and health planners to be made aware of the need for a comprehensive approach to the development of national cancer programmes. These programmes should be well coordinated so that duplication of services is avoided and the optimum use is made of available resources. Steps should be taken to limit drug shortages, and ways and means should be explored for making antineoplastic agents available to patients at a reasonable cost.

Health education

Through the mass media, a sustained and determined effort should be made to educate the public on risk factors in the etiology of cancer, its nature and ultimate effects, early symptoms, and the action to be taken when cancer is suspected. This will increase early detection and treatment. The public should be made aware of the fact that early detection is

the most important factor in successful cancer treatment and that cure is possible for many cancers in their early stages. It is, of course, essential that such health education should be matched to available diagnostic and treatment facilities.

African treatment protocols

Although most of the treatment failures can be blamed on an advanced stage of the disease and inadequate facilities, the ineffectiveness of the currently used chemotherapeutic agents also plays a part. New protocols need to be devised and tested in African populations. We know very little about how most of these cytotoxic drugs are handled by the tumour and normal cells in Africans. This means that drugs and drug dosages and tumour sensitivities should be tested to find suitable schedules applicable to Africans. This is an area in which pharmaceutical companies can participate to provide the much-needed financial support. □

Progress in family planning

The developed countries have had widespread practice of family planning, but the only country to provide services officially was Japan, which did so only for a short time in the early 1950s. In 1960, only three developing countries had population policies; only one government was actually offering family planning services; and no international development agency was working in family planning. By 1980, 35 developing countries had official policies to reduce population growth rates, and another 31 officially supported family planning activities. These 66 developing countries contained 91 per cent of the population of the developing world.

— Rashid Faruqee, in *Finance & development*, Vol. 20, No. 2, June 1983.

A place for the family in hospital life

The view that it is the family's responsibility to care for its sick members is so deeply rooted in many societies that relatives will not leave a sick person even when he is admitted to hospital. Most hospitals have not taken this practice into consideration.

Late in 1980 we had the opportunity of visiting many hospitals in various parts of the Philippines. One of the things that impressed us most, wherever we went, was the fact that patients always seemed to be surrounded by members of their families, either looking after them or simply there to keep them company, while the hospital staff accepted their presence with equanimity.

We have observed this custom in other parts of the developing world and feel that it deserves discussion, since there is obviously a great deal to recommend it. However the practice can also cause problems to the smooth running of hospital life and we propose some steps that might be taken to overcome them.

Who Should Care for the Sick?

Hospitalization removes a patient from his familiar surroundings, and can deprive him of the psychological and emotional support he needs during illness. Regular visits from family and friends are therefore very important because they help to preserve some continuity with his home life. The value attached to this continuity varies from country to country, and between ethnic groups in one country. In the USA, for instance, the Navaho Indian's con-

cept of care for the sick leads him to expect undivided attention and a certain amount of ceremony, and he therefore feels lonely and abandoned in hospital. In the south-west of that country, people of Anglo-Saxon origin prefer modern medicine and hospital care when they are sick, while those of Spanish origin look to their families for care and support.

In many parts of the Third World today, hospitals are viewed with fear as being last resorts for the dying, to be avoided at all costs. But even where this view is not held, many families are still reluctant to hand over the care of their sick to anyone else, and will bear all kinds of inconvenience, from long journeys and inadequate transport to loss of income, to remain with them during treatment. Friedl describes a scene in a hospital in rural Greece that was similar to our experience in the Philippines and must be typical of hospital life in many developing countries — five relatives of one patient seated round the remnants of a picnic on the floor, the husband of another heating food for his sick wife, and the relatives of a third looking on (1).

In the West there is a far greater acceptance of professional care in sickness than there is in developing countries. Medical care became increasingly hospital-oriented in the latter part of the 19th century, with the more frequent practice of surgery and the introduction of medical techniques requiring special equipment, highly trained personnel, close obser-

Dr Eldar is Associate Professor of Health Administration at the Ben Gurion University of the Negev, Be'er Sheva, Israel. Ms Eldar is Coordinator of Clinical Experiences at the Aliza Yellin School of Nursing, Haifa, Israel.

vation of patients during treatment, and a high standard of hygiene. Gradually the everyday care of the sick came to be seen as the responsibility of nurses and doctors rather than of families, and hospitals, including those for children, restricted visiting to a few hours a week so that it should not interfere with the work of the professional staff.

In the past four decades, however, there has been a gradual realization that this highly specialized, impersonal approach to care has not always been in the best interests of patients, particularly young children, where separation from the parent is now considered to be more harmful than the illness itself in many cases. In 1959 a committee convened by the British Government recommended that parental visiting should be unrestricted, and that where possible mothers should live in with their young children while they are in hospital (2).

In North America too, there was a general relaxation of visiting policies in the 1960s, and some hospitals both in Britain and in the USA established facilities for mothers to live in with their children. A controlled study showed that the incidence of emotional and infective complications was significantly lower in a group of children admitted with their mothers compared to an unaccompanied group (3). However a survey in Britain indicated that only

Patients' families are particularly receptive to health education, and they will take the knowledge they acquire back with them to the community, where it is most needed.

34% of mothers of one-to-five-year-old children (the most vulnerable age group) would make full use of unrestricted visiting hours should their children be admitted to hospital (4). The reasons generally adduced were: conflicting commitments at home, lack of self-confidence in the hospital environment, and lack of awareness that a parent's presence in hospital would be of benefit to the child. Other

reasons given were travelling costs and the loss of working hours and income.

Studies showed too that nurses were generally not in favour of more relaxed visiting practices, and sometimes even strongly opposed the trend: they found it more difficult to get on with their work under the critical eye of the mother, and often resented having to entrust to them the more gratifying tasks such as feeding and dressing children (3). Another study concluded that time alone would not change these attitudes and that a complete redefinition of the roles of mother and nurse in hospital was needed to overcome reluctance on both sides to extended visiting. It recommended that the mother be responsible for the physical and psychological care of her child, the nurse for professional care and for providing the mother with guidance. A recent study in the USA adds weight to this recommendation (5). It found that, given the appropriate guidance and encouragement from nurses, mothers have been able to overcome psychological barriers and give more effective help, which is of benefit to the staff as well as the patients.

For families in general, greater freedom to be with their sick relatives and to share in their care even in hospital helps to alleviate their worries and makes them feel more useful. This is particularly important to the close relatives of critically ill patients who find it hard to sit by with no effective role to play.

For a patient the transition from hospital life to home life after discharge is considerably eased if he has not been isolated from his family during treatment.

However, visitors may sometimes become a strain for both patient and staff merely because there are too many of them or because they tend to disregard hospital rules and regulations. A particular problem is posed by visitors who expect to stay with the patient throughout his hospitalization, whether or not there are special facilities for them to do so, and this is common practice in many countries. In Malawi, for instance, a patient has "guardians" who accompany him from his village into hospital, look after him while he is there, and accompany him back to his village on discharge. In the Philippines these people are known as "watchers", and they are very common

among all classes in rural as well as urban areas. Though their presence is accepted in both private and government hospitals, the watchers often cause a great deal of trouble with their many belongings, sharing the patient's bed, occupying a vacant bed in the ward, or simply spreading themselves out on the floor. In the vast majority of cases they are given no instructions on the standard of behaviour and cleanliness that is expected of them while in hospital, and they are liable to misuse toilet facilities, make the wards untidy, and even spit on the floor, thus creating conditions for the spread of infection.

Sometimes the problem is compounded by shortage of staff, for when the nurses are overworked they tend to rely on the assistance of the watchers, even though they may have no knowledge of simple nursing care or any real understanding of the disease beyond mere superstition.

In order to overcome these problems we have a number of suggestions to make. The custom is so deeply rooted in the cultural traditions of many countries that it would be inappropriate to think of curtailing it. The question is rather how to get the maximum benefit out of it. To this end we recommend that each hospital formulate a policy regarding visitors who live in and the tasks that could be assigned to them, and that hospitals take the opportunity for health education afforded by the presence of visitors.

Formulating a Policy on Visiting

Hospital administrators should decide first how much regulation of visitors would be appropriate to their particular hospital and should then consider the following questions. Should visitors be equally allowed to all patients, whether their condition is mild or severe, whether they are adult or child, whether in private rooms or in wards? Should an unlimited number of visitors be allowed to live in with the patient, or should only one visitor at a time be permitted to stay, and others allowed to be present only during visiting hours? Should living-in visitors be requested to leave the patient during physicians' rounds or the performance of procedures? Should children be permitted to live in, and starting from what age? Should visitors be allowed to bring and

prepare food for the patient? Once the policy has been formulated, written instructions should be circulated to the whole staff, and the policy should be explained to the community served by the hospital to obtain its maximum cooperation and to avoid the conflict and confusion that so easily arise. It would also be useful if hospitals could prepare simple written instructions for visitors as to the behaviour expected of them while they live in.

It is now recognized that separation of a young child from its parents while in hospital is likely to prove more harmful than the illness itself.

The next step is to consider what facilities are to be provided for living-in visitors that will not pose extra problems for the staff. Mothers spending 24 hours with their hospitalized children need at least a comfortable chair, or space and matting below the child's bed. Watchers also require toilet and washing facilities, resting space on adult wards or sleeping quarters elsewhere, and a kitchen and storeroom. All these can be very modest, and should be supervised for orderliness and cleanliness. Premises for living-in visitors within the hospital compound or the construction of a simple dwelling on a vacant plot are possibilities.

Active Role for Living-in Visitors

The type of tasks with which relatives can be entrusted will depend largely on their socio-cultural background and educational level, as well as on conditions in the hospital, but consideration should be given to the fact that they will require some training. In principle, relatives and watchers can perform simple "attending" nursing practices and household tasks, and responsibility for their training would best be undertaken by the head nurse, supported by the chief nurse's office. If the visitors were to perform housekeeping or maintenance tasks outside the nursing unit (such as in the laundry, repair shop, garden or stores) their training

would most likely be entrusted to the administrative office. One should remember that, even after they have been trained, relatives need constant retraining and supervision; nevertheless, their work would represent valuable community participation in the health care system. With the present trend for shortening the length of stay in hospital, families will be able to cope more competently during the recovery period at home if they have been involved all along.

Health Education

In most developing countries little has been done as yet to provide health education in hospitals, and the few activities that are taking place tend to concentrate on the patients without involving their families, except in the field of family planning. Yet patients' families are particularly receptive to health education, and they will take the knowledge they acquire back with them to the community where it is most needed. In addition to the preventive aspects, the health education of living-in visitors would cover care and maintenance of the chronically sick. The content of an education programme must, of course, depend on the watchers' capacity for understanding and the most important health problems of their community.

The opportunities for health education activities in hospitals are many and varied, but effective health education does not just happen; it should be planned carefully according to sound principles. Everyone who comes into contact with visitors teaches them something, and for this to be effective all personnel should be aware of their roles and be working as a team. Practical teaching and "learning by doing" are very useful; mothers of children

admitted for malnutrition, for example, could be shown how to prepare the food themselves and how to raise plants rich in proteins, vitamins, and iron in their own homes, as well as being given instruction about adequate nutrition. Other possible means of education are demonstrations, posters, reading materials, recorded talks, lectures, and films. The example set by the staff in behaviour, cleanliness of premises, and respect for the facilities should not be overlooked.

* * *

Modern institutional medical care tends to be specialized, formal and impersonal, and more disease-oriented than patient-oriented. Imported into developing countries it often conflicts with the traditional, more personal approach to illness and care that involves the whole family.

Medical and nursing staff in developing countries should therefore not focus only on the patient but recognize the traditional strength of family life. □

REFERENCES

1. FRIEDL, E. *Human organizations*, **16** (4): 24 (1956).
2. *Welfare of children in hospital*. London, H. M. Stationery Office, 1959 (Report of the Platt Committee).
3. BRIAN, D. J. & MACLAY, I. *British medical journal*, **1**: 278 (1968).
4. MEADOWS, S R. *British medical journal*, **2**: 813 (1964).
5. ROSKIES, E. ET AL. *Medical care*, **16**: 765 (1978).