Lessons from the Wash House

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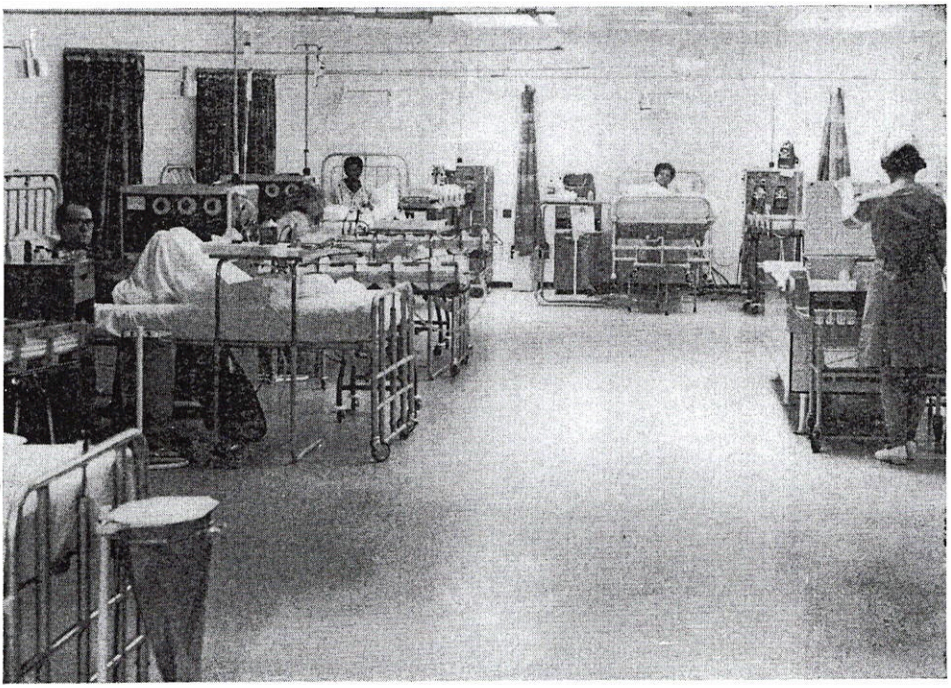


THE UNIT, SHOWING FIVE OUT OF THE TEN BED STATIONS

The purpose of this article is to put down some of our first impressions of Regular Dialysis Treatment, (R.D.T.) at King's over the last three years and to concentrate on those areas of general interest which we would like to share to arouse comment and discussion in other areas who have similar problems. The advent of R.D.T. has been made possible by technical advances, political pressure and the willingness of staff to embark on a procedure not without hazards to themselves and the hospital group as a whole.

The technical advances include the construction of circulation access sites via shunts or fistulae, the development of machines and kidneys to achieve satisfactory replacement of some aspects of kidney function and the increasing success of renal transplantation. The political pressure has come from the general population and groups of interested physicians and surgeons who can fairly say that lives can now be saved and rehabilitated fully by the provision of money for facilities and staff alone. Each year 60/million of the population between 5 and 55 die of correctable renal failure in the S.E.R.H.B. area. This means upwards of 200 people will present for help which, if shared between four units, (Guy's, King's, Brighton and Canterbury) would mean each one dealing with a new patient a week.

Selection. Multiple Hurdles rather than a Committee

This is one of the most difficult points in the treatment of patients with end stage renal disease. One of the features that we regard as highly important in the selection of patients is the will to live. This bears no relationship, necessarily, with age or disease process, the presence of spouse or father and mother in the family or even with a place to live. This is one of the difficulties that all Units face, that although it is easier essentially to treat patients with only one disease such as end stage pyelonephritis who belong to a stable family with good accommodation it means that a proportion of patients have to be rejected who do not fulfil this criteria. We have adopted a different approach, partly experimental, partly borne out by other Units both in the States and in this country that, although these criteria make selection easier, they do not in any way ease the ethical burden of a large number of patients presenting with renal failure who we now know can be helped to live a purposeful life, admittedly restricted by the limitations of regular dialysis. In many other ways their lives will be more full and complete than those with paraplegia or difficulties with respiration where large efforts are made in the community to rehabilitate them.

Age itself carries an ever increasing problem with vascular disease and certainly it has been our experience that the older patients have had more difficulties both with cerebro vascular complications, long standing heart disease and also difficulties of shunt and fistula construction. However, these in themselves are not insuperable. As we have no strict criteria it widens the field considerably for the number of patients that can be taken on for dialysis.

The second problem is how long they can be kept alive while waiting for a particular space and in this sense there is selection at this point in that the number of patients who can be maintained on peritoneal dialysis depends almost entirely on the number of beds available in the hospital as a whole and the number of nurses who can be diverted to this technique, although we have benefited recently from the development of automatic peritoneal dialysis machines which take a great deal of the labour out of the procedure.

At this hurdle, when all the available beds and staff are occupied in keeping patients alive on peritoneal dialysis on the wards, patients are refused on the telephone without being seen simply because there is no more room. We are trying to keep a list of such patients but it is our experience that for every five offered we are able to perhaps offer some help in the diagnosis and possible acceptance onto the programme to three of them.

The next hurdle is one of persuading the nursing staff within the Unit that a particular patient should be taken on sooner rather than later, for every week's delay in some cases renders the patient's morale lower and also his nutritional state suffers from continual peritoneal dialysis unless a deliberate attempt is made to keep the protein intake high. While waiting they are more prone to infection and pulmonary collapse and these again add both to the nursing problems and also the cost of maintenance on peritoneal dialysis.

The Unit and Ward as a Family

Many analogies have been drawn between the ward sister and the doctor as between mother and father of a family and although there is not much access to the sort of discussion that goes on between a mother and a father as to whether they should accept and have more children, there are many similarities; one may be keen on an increase in the number in the family for the sake of accepting more responsibility, more challenge, more variety

and more opportunities, but on the other there is the conservative attitude, perhaps taken more by the mother, that if more patients in this case are taken on those that are already within the family will suffer—they will not have so much care and attention, they may be pushed out of the home more quickly, they may have their training periods cut short and in this sense those that are on the programme must suffer if an increasing number are taken on too quickly for dialysis. It is at this point that many of the tensions develop but it has been a working principle that the nursing staff basically have a say in how many patients can be treated in the Unit safely and without undue stress. Over a period of time they have seen the advantages of taking patients on early rather than late as they come down in a better physical state and are more easily trained and more quickly got home and their medical problems are lessened. However, in a number of patients who we have treated they already arrive with advanced disease which has made dialysis only a prolongation of a slow death. How to pick these out is difficult but we have refused to treat a number of patients for these reasons alone, advanced cardiovascular disease, schizophrenia, depressive episodes leading to dietary neglect, diabetes with eye problems are some examples.

An Extension of the Nursing Attitude

The full quota of Nursing Staff in the Renal Unit is thirteen, one Nursing Officer, two Sisters and ten Staff Nurses. There are no Student Nurses, all are S.R.N. There are no requirements for previous renal experience. The course lasts six months with a probationary period of two months. Nurses' uniforms are based on the American style—blue cotton shift type dresses with disposable paper caps, ordinary stockings and 'clog' type shoes.

The nurses are taught not only the nursing care of the patients but also how to build a Kiil or artificial kidney, how to test it is safe for use and how to sterilize ready for use and, armed with this vital knowledge, teach the patients and their relatives. The nurses are taught all the vital nursing procedures needed in dialysis and they in turn teach, explain the reasons why and how and also try to answer any fears and problems that the patients might have especially in the early stages of training.

Knowledge of the three types of machines is useful to the nurses and with the help of the Unit technicians they are able to learn how to fix small discrepancies that might occur whilst the patient is on the machine, either in the Unit or in the home and this knowledge is passed on to the patients. Experience is the major factor in training up and teaching the work in the Unit to new nurses. They are encouraged to observe and then take part in any emergencies or tricky procedures as early on as possible as few incidents are similar and much is learned from each new happening.

There is minimal sickness amongst the nursing staff and this could be partly attributed to the excellent off duty times in the Unit—it is a five day week, Monday to Friday with a 38 hour week. This enables them to get away from the work and their colleagues and also to be able to know their on and off duty well in advance so that they are able to plan more outside activities.

Working in the Unit is not every nurse's idea of true nursing—it is very different in many ways as much of what is done by the nurses in the Unit is usually carried out by doctors on the wards and also nurses have to have some knowledge of working machines and this is extremely alien to most of them. But we believe that the nursing of the future is based on the type of nursing that is done in the Unit.

Once on dialysis within the Unit the nurse has to work towards the patients becoming independent of her which is an extension of the usual nursing attitude to patients who are seriously ill and this requires a persistent drive to make the patients independent. They are soon introduced to making and taking their own observations of pulse, blood pressure and blood flows. They learn to withdraw fluid from their bodies by increasing the negative pressure across the dialyser and, in this way, take a hand immediately in their own treatment. This is pushed to extremes in many cases where patients will learn from dietary modifications and drug therapy to keep their blood pressure within limits. They will soon prove to themselves the importance of sodium and fluid restriction and the care that they have to take to keep their electrolytes within reasonable limits. This leads to considerable alarm among the new nurses joining—that the patient knows far more about his treatment and management than they do and some have become extremely independent at home and their visits to Out-patients take the form of suggestions as to modifications of their own treatment to which the doctors may or may not agree.

Co-operation with the Services outside the Hospital

Dialysis provides a unique opportunity for collaboration between the Health Services outside the hospital. Perhaps as never before General Practitioners, Medical Officers of Health, District Nurses and others have been so involved with a group of patients. We have benefited from the excellent collaboration of Medical Officers of Health in several counties and we have had over 100 District Nurses on Day Courses and longer courses pass through the Unit in the past two years. Several practitioners have spent the whole day with us seeing their patients being treated and have enjoyed seeing techniques demonstrated first hand. In no sense have these groups taken over the treatment for which we are entirely responsible but many patients have benefited from the medical and social support of people in their own towns and villages who know about the procedure and know about some of the difficulties. In this way dialysis may well point the way forward as District Nursing continues to claim a large proportion of nurses trained in hospital where they feel they can no longer in many areas in hospital form part of a close knit team of doctors, nurses, and the patient which appeals to them both from the point of view of independence and from status in that they really can manage and help patients and make their own decisions from week to week. Our dietitian has a lot to do in helping patients and local nurses understand the intricacies of renal diets.

Psychiatry is relevant

Several of our patients have needed psychiatric help not only for organic psychosis but also for support in the family situation where the stress of a chronic illness has come unexpectedly hard on the unaffected spouse who is already trying to cope with new techniques, to look after a family and to maintain the family income. There is no doubt that dialysis brings with it extra expenses and a total reorientation of family life. Holidays become a problem, the effects on children are difficult to estimate but many children look upon the long absence of a parent as indicative of an early death and one child was heard to remark that 'there was no need to plant vegetables in the garden as Daddy would not be alive long enough to enjoy them', and this area of medicine needs more study. The patients are not the only ones who require help and we have been greatly indebted to a series of Senior Registrars from the Maudsley who have not only seen our patients and sat in our Unit meetings but have also been able to provide seminars for the nurses and staff so that the problems that patients bring up of dependence and marital stress can be

discussed at length with them. Some patients have evoked considerable hostility among Unit staff and this has had to be discussed and, where possible, worked out. The problems of transplantation and the donation of organs by living relatives raise feelings of dependence and guilt which are difficult to resolve.

Kidney Assistants

Artificial Kidney Assistants, of which there are five—three in the morning and two in the evening, are of vital importance in the Unit as they are the most concerned with the building, testing, sterilizing and putting lines on as well as stripping and washing down the Kiils in the Unit. They also teach these procedures to the patients in training and their relatives and new nurses arriving in the Unit. They are involved in mending and supplying new Kiils to the home patients if the present ones do not function properly. This job, although extremely important, can be exceedingly boring and tedious and it must be mentioned that without the support, interest and loyalty from these Artificial Kidney Assistants who work for the patient as well as the nurse, the Unit would move much more slowly.

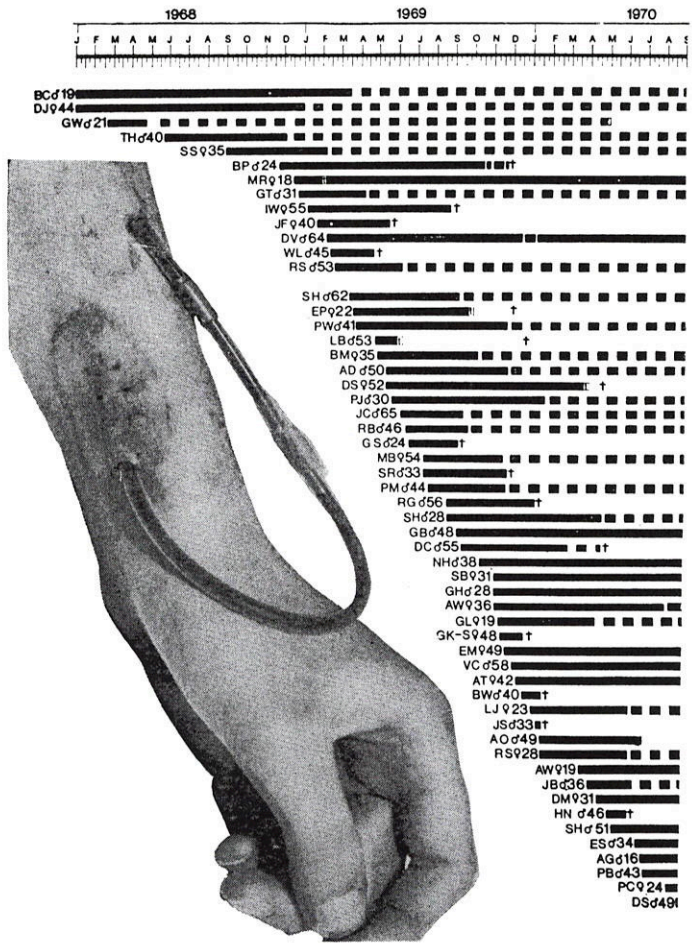
Everybody should know everybody else's job

In dialysis the training of the patient involves a total instruction of all aspects of dialysis both technical on the machine, on the problems of anti-coagulation shunt care, sepsis control, antibiotics, hypotensive drugs and We have found over a period of time divisions of labour between technical staff, nurses and doctors just do not work. There are no aspects of management and treatment which are the sole prerogative of anyone within the Unit. This has caused some concern at times particularly among the nursing staff who feel that some aspects of treatment such as the de-clotting of shunts or the treatment of hypotension should be left to the doctors within the Unit. However, in certain situations a trained nurse can do these tasks so that the patient can get on with dialysis treatment with the minimum of delay. Patients have been taught to de-clott their own shunts at home and in certain circumstances have been able to use thrombolytic therapy such as Urokinase so that the administration can be given over the telephone.

The technicians perhaps visit the home more than anyone else and are asked questions about sodium concentrations, hard water, diet and frequency of dialysis which again, within the limitations of their own understanding, are answered while adequate communication between nurses and doctors and the patient is maintained on dialysis on the telephone. We have successfully treated massive haemorrhages, large air emboli, left ventricular failure, clotting episodes and hypotension over the telephone and this has given us some confidence that the major emergencies that can occur on dialysis can be successfully treated at long distances. Our furthest patients have been in Dorset and Norfolk and after initial problems have been solved these patients have given much less concern than some of those nearer at hand.

Transplantation—The Answer to the Problem of more and more

The open ended nature of dialysis treatment raises large fiscal problems for, if the number of patients who are presented each year go on growing, the number in the home can have no ceiling, but this means that the budget must be an open ended one which neither the authorities within the hospital, the region or within the Ministry of Health alone can face and so there has been considerable pressure put on patients that, in suitable situations, transplantation would be a solution to the build up of a large number of patients on long term maintenance dialysis at home.



Turnover of Patients in the Unit over a 2 year period and the shunt system which has made this possible.

However, many patients have opted at the present state of the art to remain in the home and this is a problem which cannot be solved by forcing transplantation on the patient because, although the survival figures for both forms of treatment are parallel, the older patient may not necessarily do so well on transplantation and these do form a significant proportion of those taken on to dialysis. Some Units have solved this by taking only those under 35 but how this can be squared ethically with the long term survival of patients much older than this is one to which we do not know the answer but we have felt that we cannot take such a strict attitude while finances are still reasonably fluid.

Administrators at the Coal face

We have derived the utmost help from the Unit Administrator—he has blood on his boots like anyone else in the Unit. He has immediately seen where hold up in supplies leads to patients' discomforts, where delays in conference and committees works out directly in morbidity and death. The rule book is made up to help the staff do their jobs more efficiently, not just to cut down expense by attrition. We have been able to see that personal communication in the County Council rooms, the lobbying of Councillors and

direct approaches to Medical Officers of Health pays off far more than circulars, letters and telephone calls so beloved of desk bound administrators. The judicious leaks to the press, the well timed lunch party for behatted housing representatives have turned the tide and even the direct approach to a past minister has eased the situation on occasion. We have learnt from hard experience that improvements in the service only come when crisis brings the administrator to the Coroner's Court or the Trade Unions point out the anomalies of practice that have led to a resignation.

Stresses and strains within the Unit

The techniques of dialysis are quickly learnt and the stresses mainly come from patients who do not progress as rapidly as they should or are subject to chronic problems of anaemia, polyneuropathy and anorexia. Several patients have obviously felt that their lives were not worth prolonging and have, over a period of time, continued to lose weight and eventually, although tube feeding has been resorted to, they have succumbed to malnutrition. This has been the case particularly in the single person of whom we have had three deaths in those under 40 with this problem alone. The other situation is where the marital state deteriorates steadily and the support of a relative which at first was thought to be viable no longer appears possible with the passage of time and these virtually single people have no hope or very little hope of getting home on their own, particularly with fistulae and they will provide a hard-core of in-patients. We have found that night dialysis is the most suitable place for such a group of patients where they have been trained to virtual independence and, although this has caused some alarm, we have found it possible to train up to five patients at night completely unattended by nurses or doctors, although the latter have been immediately on call where the need arises, but with the assistance of a Night Artificial Kidney Assistant on duty. The stress of long term treatment of the more difficult patient has led to staff resigning after the minimum period in the Unit where there have been long delays in home modifications and where the patients themselves have become difficult. Technicians have found the hours of work and the demands on their time excessive and if they have had a long period of industry, find it very difficult to adapt to the very elastic hours that are worked in the hospital situation and several of these have resigned and found work outside. Doctors have expressed their feeling that they cannot continue with this limited area of work month after month, year after year. This is perhaps when research projects surrounding such patients have a great part to play in the future but the employment of part time clinical assistants has made the work in this direction slow and particularly difficult.

Summary

Perhaps then we can enunciate some of the lessons that we have learnt in the dialysis field that might well have application in a wider area.

The first is that nurses should have a say in the amount of work that they do and the rate at which patients are treated and turned over.

More and more parts of medicine and treatment can be turned over to the patients and their relatives management themselves, such areas as hypertension and the dietary management of various diseases immediately spring to mind for many of the supervisory acts of doctors in Out-patients could well be monitored by patients themselves if they were taught the meaning of blood tests and other features of their treatment for which they usually attend clinics.

The co-ordination of the large forces in the Public Health and District Nursing fields should be actively sought in other branches of medicine so

that the community resources are used to the full.

Psychiatric insight has been valuable at every level and the feeling that there are areas for which psychiatry has nothing to offer must disappear quickly.

A new generation of nurses is appearing who, in many areas, will take over the functions of the doctors once the decisions have been made so that the drug therapy, dietary alterations, samples of blood can all be determined at the nursing level releasing the doctors for the more sophisticated tasks of diagnosis.

The financial aspects of medical care must be discussed at all levels of the community and society so that they are informed of the true cost of medical care and that the choices and decisions of such care are made at a political level and really do not necessarily depend on constant agitation by the medical profession themselves. This is partly the problem for the doctors to educate the public in the cost of medical care so that the individuals themselves can decide as to how much of their lives and work should be spent in providing not only for their own illnesses but also for those in the community less fortunate than themselves. We feel strongly that the administrator who tries to keep to a politically determined budget in every direction is responsible for a steady devaluation of medical care and those who carry it out—cheap is often nasty.

The provision of hotel care has been a great benefit to the management of patients who are reasonably well to look after themselves but unable to be completely independent at home. We have used hotel facilities extensively for patients waiting to return home or, in these cases where they have lived at long distances from the dialysis centre, they can be accommodated there while their homes are being modified. This seems applicable in many areas, particularly in medicine where the patient is undergoing investigation and does not require frequent monitoring or the administration of drugs which must require nursing and regular medical attention.

Where nurses are in short supply, as has occurred on occasion in the Unit where the number on a shift has dropped as low as two, the patient's relatives have been called in to help with as many procedures as possible. They have fed the patients, have carried out their many nursing duties and, where trained, have managed to carry out the dialysis completely without nursing help. This applies particularly to patients at night where, on occasion, there has only been one and the relative has stayed in the bed next to the patient and has acted as a nurse throughout this period. We are sure that where relatives see the need and shortages they would be trained to care for the more long term sick in less expensive accommodation.

Hepatitis—everyone who works in this area is aware of the risks that this disease brings, particularly those who are ill with uraemia and those who have worked long hours seem particularly susceptible to this common disease. Some staff have expressed deep concern when a patient has developed hepatitis and this has been talked through and the vast majority of staff have accepted this risk as part of a medical task, as they have accepted similar risks in the past in dealing with such diseases as smallpox and tuberculosis. The enormous acceleration of interest in hepatitis has gained from the experience of dialysis units and we are now beginning to explore the use of frozen blood, prophylaxis using gamma globulin and the early detection of the disease by screening for Australian and other hepatitis associated with antigens. No disease process is without its spin off.