SPECIAL ARTICLE

THE SOCIAL ISSUES AND ETHICS OF END STAGE RENAL DISEASE (ESRD) MANAGEMENT

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I am sensible of the high honour that the organising committee of the 4th Colloquium in Nephrology has bestowed on me by asking me to give the first Foundation lecture. Being Asian, it had seemed extraordinary to have a lecture named after oneself and most unusual to be first lecturer. I suppose my cultural roots did not permit this immodesty and so I duly protested that there are far abler men and women in the region and beyond. But Dr. Leong and his colleagues did not feel the same and proposed that I return their compliment by accepting this task which to say the least, has become a millstone round my neck for longer than I care to admit. Since I have the support of my fellow countrymen, my presence here is also in acknowledgement of their unstinting support since 1961 when we ventured into nephrological waters and did not know then the depths we were treading. I feel rather humbled by the occasion not only because I face my peers who are so distinguished in their special fields of nephrology but because having been a generalist, I cannot consider myself adequate to increase knowledge in their subjects. However I do have an advantage of being an inside observer for quite some time, occasionally helping to stir the broth. Some unpalatable truths have surfaced now and then to disturb my conscience and I believe the profession's as well as in presenting these issues with my thoughts I hope the Colloquium may be able to resolve some of these conflicts with wisdom and understanding.

In the 1950's I watched my younger brother die of uraemia. My colleagues and I had nothing to offer him medically at this stage and I suffered with him in the weeks before the end. I saw his personality and mood change. I saw him fighting desperately to keep his senses clear, all to no avail - an usually vibrant, lovable person became moody, hostile and increasingly difficult. It was hard dying and I promised that I would find a better way or a more dignified way of exit for others in the same plight. My brother had a nephrotic syndrome that our Western medicine at that time had no real treatment. The senior specialist who had been my examiner in the finals had given no hope after exhibiting the time honoured remedies. So my brother had committed his soul to God, discharged himself from hospital and sought herbal treatment from a spare time Chinese Physician who so removed his oedema and proteinuria that he passed his medical examination to study in U.K. The main ingredient of the remedy is so revolting that I shall not name it but my brother had no relapse for three years in England until he completed his study. My brother was an ordained Minister and in his lucid moments that were few and far between in his uraemic stupor, his faith shone through with compelling clarity. It is keeping faith with my promise that I later went to North America in 1959 on sabbatical leave and started on my search. Several years later in 1961 we started on our haemodialysis experience. Then with somewhat more confidence and after having visited over twenty world centres I decided to start our ERSD programme in 1968 and invited Prof. David Kerr as visiting professor to advise us. It did not occur to us that we would be embarking on something almost alien to our medical training and experience, requiring not only large leaps in scientific knowledge involving new disciplines such as immunology and the technology of water purification, dialysate manufacture, membrane kinetics etc, but also management skills and training of renal and intensive care staff from scratch. In other words a new breed of health care practitioners after prolonged gestation and painful labour, was born of Western science, Christian compassion and local pragmatism, and so came into being in Singapore.

Although the artificial kidney had been constructed and used in the early 1930's, (1) the concept of regular dialysis for ESRD took form only twenty years ago. The initial euphoria that the machine promised an end to ESRD has given way to misgivings because of many factors hitherto unknown so that the profession could scarcely be aware of them. Not the least among these are social issues creating psycho-social problems and dilemmas of medical ethics.

There is no doubt that vast knowledge has accumulated since nephrology became a discipline in its own right. In a way nephrology has arrived as a medical science but we have arrived in a rather inappropriate time in human history when a new morality is threatening to swamp the traditional conservative concepts of the sanctity of life, the permanent monogamy in marriage, the importance of the family unit and the integrity of the doctor in respect of the trust and confidence engendered in his patients. It is patently clear that the conservative attitude of physicians has been affected by this philosophical shift to materialistic humanism, 'where situational ethics have replaced absolute standards of right and wrong. The limitations and relativities of modern science are being exposed by the physical reality of ERSD in everyday practice. The Hippocratic oath and our Code of Ethics, do not give ready answers. Dr. Hamburger in the CIBA Foundation Symposium on 'Ethics on Medical Progress' in London in 1966 said, "A practical consequence follows immediately; the ethical training of a doctor cannot be limited henceforth to the teaching of a few ready made rules. It should also encourage a lucid inner understanding of the relationship between doctor and patient, of the dignity of the latter and of the extent of the services which the former can offer. In this way will be developed more surely than by a code, the sense of personal responsibility essential for every doctor......... to produce men who are strong, who are not only honest and just in thought but efficient in action, to develop in them an awareness of the value of human life, to convince them that their vocation is an extensive obligation to the individual and the group; such it would seem, are the best means of facing the ever increasing difficulties of medical ethics."

Codes and declarations cannot inculcate a deep responsibility. Some like Lord Lister would apply the Golden Rule in the art of healing "Put yourself in the patient's place". Medical ethics are in fact framed by the value systems and thought forms of the society. We have through Western medical training inherited from a post Reformation European world view which in turn received its heritage from Judaeo-greco cultures centuries past.

The new morality claims that the medical ethics of saving life is historically and sociologically too far removed from the modern industrial age. Is it? Can each doctor be a law to himself, deciding which patient should live by dialysis and which to die by refusing to put him on the programme? Again should the doctor stop dialysis and let the patient die when he is clearly not improving but deteriorating? It is difficult enough to define circumstances in which dialysis in any form and or transplantation should not be used. The present dilemma is not a simplistic life-and-death issue because the doctor in our region has also to practise triage which compels him to make choices in the face of limited resources. Can the doctor discover his own ethics by trial and error? Even when the strictest criteria are set up within tight limits of age, say 15 to 50, restricting dialysis to those without systemic disease, with good scores for psychological and social work-ups, there will still be too many for the physician to handle. In the case of Singapore, about 150 will fulfil the criteria just mentioned and only 10% of them would find places in the programme. If we come to grips with this problem often enough, we face the real issue that ESRD is an automatic death sentence for the innocent sufferers. Why should a life-and-death decision be made by the physician alone? Should not the society share the burden? And so the society should also have a choice in policy and philosophy in preserving life that is supposedly precious as it has a choice in applying the death penalty for crimes of murder and drug trafficking. In comparing dialysis treatment with other types of medical treatment requiring large expenditure of money, e.g. chemotherapy for cancer or lymphoma, their poorer survival rate is good enough reason why dialysis should not be made a special category. The danger is that we are coming close to putting a price tag on life without defining what life is worth. Medical audit claims that dialysis treatment is not cost effective but for that matter so it was with any major scientific discovery in the initial stages. It should be stressed that dialysis is no longer considered as crisis intervention for ESRD, it is the treatment of choice until transplantation is available.

When there is divergence in policy or principle between the health worker and his government, it is the patient who suffers. The government is concerned lest there be an unbalanced development beyond its economic resources, the physician is concerned that his patients would be left out in the overall planning which would emphasise large prevention programmes rather than a high cost programme for a few. In a developing nation with limited resources for health care, public health programmes to eradicate communicable diseases deserve top priority. But when a country becomes more developed, health care often remains a low priority in relation to defence and education and therefore its cinderella areas such as geriatrics and psychiatry get thinner slices of the financial cake and dialysis hardly any. On the other hand it is claimed that high technology medicine seemingly tries to free man from his appointed destiny by excessive reliance on support systems. Surely this is not the case with ESRD because the patient is freed from certain death to lead a normal existence by less than twenty hours support a week from the machine. And many of the patients are in the prime of life with vears of contribution to the society ahead. What is certain is that in any culture, man has the primodial instinct to survive and until there is a better proven method, he will not want to be denied dialysis in ESRD.

While we are frustrated by our circumstances in turning away the large numbers who require dialysis, we can but wonder why in the States senile patients in 9th and 10th decades of life, cases of paralysis after stroke and metastatic cancer are being dialysed (2). But if this is tantamount to dialysis-on-demand in one country it is still no reason why most developing countries are treating less than 10 per million population by dialysis. We should however learn the strength and weakness of transplantation/dialysis programmes in the world scene and apply the appropriate lessons to our own systems. It was less than 10 years ago in 1972 that the US Congress passed Public Law 92.063 extending social security medicare benefits to dialysis and transplantation. By 1980, 50,000 patients comprising 0.2% of the active medicare population were consuming 5% (or more than 1 billion dollars US) of the total medicare budget. By 1986, the projection is 2.5 billion dollars for 65,000 patients in USA. Such a profitable reimbursement has no doubt contributed to the growth of proprietary dialysis centres which treat about 25% of patients in USA. On the other hand it is claimed that dialysis for profit has resulted in more economy than in non profit centres. While this strengthens the case for medical audit in USA, it cannot apply to countries where dialysis is restricted severely. In 1979, haemodialysis patients per million of population were 205 and 235 for USA and Japan respectively. The trend in acceptance rates for older patients is also seen in West Germany, France and Italy. However few persons above 55 years were accepted in UK although there is a perceptible trend to admit up to the age of 65 years which is the natural retirement age. Significantly even in Europe the dialysis rates were 13 and 10 per million for Hungary and Poland respectively (3).

In India, dialysis for ERSD patients is supported by the State only if there is a potential for live donor transplant. Currently 50 - 100 patients are receiving dialysis but over a 5 year period 1974 - 1978, more than two-thirds of 1046 patients received treatment for only a brief period (4).

In Malaysia preferences for heamodialysis is given to ERSD patients with well matched living related donors which resulted in 32 living related transplantation between 1975 and 1979 (5).

In the Middle East oil rich countries, although there is no financial restraint, there is a lack of skills in servicing and maintenance of equipment and staffing of dialysis facilities. Thus Libya has 2 dialysis centres for about 40 patients for a population of 2.5 million but there is yet no transplant programme. Iraq has 9 locally staffed dialysis centres catering for 160 - 250 patients but there are limited transplantation facilities (6).

Cadaveric kidney transplantation has not been carried out in Egypt where 60 live donor transplants have been done and 220 patients received dialysis in 18 centres including 7 private ones.

In India with a population of over 600 million only 12 (13.3%) of 365 transplants over a 5 year period have been from cadaveric kidneys (6).

Cultural and religious reasons have been given for the scarcity of cadaveric kidney transplantation in Asia. It is also true that the live donor programme in Asia has been successful in countries where there are strong kinship ties that span 3-4 generations in large extended families. Where there is strong family support, where the roles are clearly delineated in the family system the problem of ESRD may be more community or family related than individual related. The family rather than the individual manipulates the environment. There is reason to believe that in the East there is co-operation and subordination of the individual to the community whereas in the West and especially USA values such as individual responsibility and initiative aggressiveness and competitiveness are highly emphasised. Thus if cadaveric kidneys are hard to come by, one should press on to live donor transplant. This has been the experience in Singapore where 22 cadaveric transplantations were done from 1970 to 1978 but none thereafter. In the past 3 years 60 living donor transplantations have been done with good success.

There are a number of reasons why cadaveric transplantation is the obvious choice in developing countries. Apart from the fact that the harvest from fatal motor and industrial accidents could furnish an adequate number of kidneys to meet the demand, there is the cheaper overall cost. In Singapore a cadaveric transplantation operation could cost the patient half as much as a live donor transplantation but the costs vary tremendously i.e. about US$300 to US$10,000 depending whether the recipient is fee paying (for operation fees, investigation, semi-private or private rooms) or not.

It is encouraging to note that some countries have been able to perform more cadaveric transplantations than even haemodialysis in terms of patients per million population. Thus Australia has 80 per million on haemodialysis but 91 per million for functional transplants on 30th April, 1980. What is most remarkable is that some relatively small countries have been able to achieve higher figures for transplantation than heamodialysis. The respective figures per million population are 95 and 75 for Denmark, 67 and 62 for New Zealand, 45 and 30 for Iceland and even Cyprus has 10 and 5 per million population respectively (3).

SOCIAL ISSUES OF DIALYSIS AND TRANSPLANTATION

Creating a truly egalitarian system which gives everyone an equal amount of health care services would be unfair according to Veatch (7). Veatch instead proposes that everyone has a claim to medical care needed to provide an opportunity for a level of health equal as far as possible, to other people's health. The "egalitarian" principle differs from the classic utilitarian one in that it does not consider the good of all the people. It would preclude expensive treatment such as dialysis.

Who then should pay for dialysis and for new life saving measures that modern technology offers? For example, widespread of oxygen will add years of life to those with chronic lung disease (8). Liver transplantation has improved chances of success because of cyclosporin, but it would cost $40,000 US. Likewise bone marrow transplantation following total body irradiation may promise cure of leukaemia, but at a cost of $60,000 US. Neonatal intensive care in a sophisticated setting could save premature infants. An example of such an infant weighing 1 lb 13 ozs at birth was cited. Intensive care treatment kept him alive until he could be taken home but his medical bill totalled $344,000 much of which was paid by public assistance when the parents exhausted their savings and resources. Because of home problems it would take $7,000 US worth of equipment and $21,000 US a year for nurses to enable his parents to take him home. He cannot kneel or stand. This illustrates the problem of allocation of extraordinary amounts of money and resources for an uncertain outcome at best (9).

Recent reports in rehabilitation in dialysis suggest that the patients may be left with severe disability preventing ordinary activities much less returning to useful work (10). Availability of unrestricted funds is being examined by the Reagan Administration. Changes in the philosophy and funding of federal health programmes will lead to harder choices concerning who will benefit and what benefit must be derived in order to achieve 'prolongation of life.'

The problem of transplantation includes several issues:—

Is it right to harvest organs from a 'brain dead' person for the benefit of others? This is the basis for a 'contracting-out' legislation which would prevent the State to use the organs of persons pronounced dead in a hospital setting. Such a person would have contracted-out, that is, notified the State that he will not allow his organs to be used for transplantation at death. Several countries have passed this contracting-out legislation. Sometimes it is asked "Is it right to turn off the machine and so irrevocably killing the patient."

The fact is that brain death is not a moral issue. It is a clinical issue. Once the diagnosis of brain stem death has been made, the patient is dead even before the machine is turned off. Indeed it could be asked if it is morally right to keep the human body alive on life support machines when the brain is dead.

Notwithstanding the success of live donor transplantation in the past 3 years, we felt that the cadaveric transplantation was the real answer to ESRD in Singapore. A donor campaign had been started some years back, using both the media and talks to community centres and secondary schools. The result was discouraging - slightly more than 2,000 cards were signed up. There has been no cadaveric transplantation for the past 3 years. It was noted that despite a code of ethics allowing the diagnosis of brain death, doctors felt that they were not sufficiently protected against litigation if they used the Royal Colleges' criteria. The National Kidney Foundation made this a matter of study and investigation and representation was made to the ministry by the hospital staff. Finally, the National Kidney Foundation requested to see the Minister of Health and presented the possibility of a contracting-out system as practised elsewhere. Perhaps it is premature socially and politically but in the context of many South East Asian countries, it is a move in the right direction.

In USA, the need for more cadaveric kidneys has promoted the Organ Procurement Foundation, Kidney Recipient Pools, Networks for organ sharing and a new breed of personnel called Transplant Coordinators. Even with all these systems it is the more tragic that as many as one-third of the harvested cadaveric kidneys are not used because of improper retrieval, damage during perfusion or transit, or simply because time ran out while a suitable recipient is being found. Perhaps this is largely due to the lack of a truly national donor organ sharing system.

Within the framework of the South East Asian region it would seem necessary in the near future to form a South East Asia Network for Organ Sharing (SEANOS). Such a system would reduce the unusable kidney factor because it would choose the best donor recipient match through its on-line computer. The region could have its own protocol covering pretransplant blood transfusion and minimal match standards for HLA, A B and DR determinants. Graft survival is improved. The WHO Immunology Laboratory in Singapore already performs HLA typing for the region and could go on to a HLA-DR system. When it moves in the near future to a new base at the National University in Kent Ridge, it could go on line with the computer facilities already available there and be linked to regional centres. However such a system presupposes that there will be a recipient pool maintained on dialysis or CAPD. This pool need not run to the thousands. Even a figure of one hundred would give a fair chance of a full house or identical matching. But there must be a suitable 'climate' of response from the medical profession, governmental authorities and the public. Logistic problems such as air transport, kidney banks and rapid communication are more easily met.

SOCIO-CULTURAL FACTORS IN DIALYSIS

As in other major chronic diseases, the management of ESRD is also affected by socio-cultural factors. Physicians in our culture are no longer mystified by the large number of relatives who seem to appear from nowhere when a member of the family or clan is threatened by a fatal disease. When a drastic type of treatment is offered, the family or clan members invariably form an adhoc committee to consider the options. If the senior members are highly suspicious of hospitals and machines, the poor patient could be discharged at own, i.e. family's request, and be subject to folk medicine, mediums and bomohs and psychic healers. Illness is viewed in many parts of the region as a family concern in terms of the choice of healers and economics of payment. Rather than keeping the family at arm's length or more, the wise physician must communicate patiently and wisely. Certainly the family and patients alike are overwhelmed by the thought of living by virtue of a machine. Thus the need to eliminate high potassium foods for instance require drastic changes in eating habits and family life styles. There are definite constraints in a dialysis life that require a long term adaptation. The patient may come to resent the machine for giving him a castrated self image. "I am not a man or human being." Many patients learn to compensate, even look upon the medical staff as parental surrogates. In general married men and women are more co-operative, more interested in learning about their machines, more independant, more cheerful, active and sociable.

However there are serious setbacks in dialysis treatment. We could measure quality of life by indices such as work function, activity level, psychological status and sexual functioning. We could grade each activity from no limitation and down the scale to serious limitation. Staff soon become adapt in predicting adjustment scores by empathising with the feelings of the patient - hope and optimism being good predictors. Well meaning relatives and friends may express sorrow or pity thus reminding them of their condition and bringing up emotion. The well stabilised patient would like to consider himself normal. Spouses may continue to feel threatened by the patients' vulnerability.

Informed patients' and spouses' participation in his treatment plan would remove such fears, but dialysis staff should be aware of the patients' problems and encourage them to share their experience with other patients and staff in the centre or with family members when he is on home dialysis.

Peer support groups or self help groups are great sources of encouragement, but I believe the patients would value sessions where the Sister-in-charge, the nephrologist and the renal technician could explain about the disease, the objective and the technique of dialysis and the features of the machine. Sometimes the dietician and medical social worker and even the visiting psychiatrist could be brought in at appropriate times. While the sharing session would provide the camaraderie and even caring for one another the prime objective would be to allay the mental and social stress that weigh on them. Complaints about the dialysis unit must be heard and the seeming distance of the staff could be removed by merely dealing patiently with complaints. Outings with other patients and the staff or members of the Kidney Foundation could restore confidence and feeling of community. While the dangers of dialysis osteomalacia, subdural haematoma, aluminium intoxication are real enough and are tackled by the medical profession, the patterns of social stress caused by 'fusing' man and machine for long periods have not been adequately studied. We tend to think that patients should be grateful that their lives are saved and they should not expect much more.

THE CONTRADICTIONS OF DIALYSIS TREATMENT

One of the effects of dialysis treatment is the loss of identity as man and machine become one unit. During dialysis, body, machine and disease are 'fused' into one, and the patient's individual uniqueness is lost to himself and even to the observer. He sees his life blood flowing out of his body through plastic tubing into the machine and often wonders, "What if the machine stops, or if there is electrical failure or a water shut-down, or if the house catches fire?" The renal staff assumes an authoritative role in his life and sometimes he ponders, "Is the nurse angry with my complaints; will she ignore me if I become angry?" Then he feels that members of his family, having pooled their total resources to put him on dialysis, may resent his living. He is confused by the magnitude of his debt to the family and may hold inner resentment and guilt against himself for causing this social upheaval. He is often unemployable in a job-scarce climate especially if he is engaged in unskilled labour. His relationship with his wife might suffer if she has to work to support him in addition to helping him use the machine in a self care programme. His libido may decrease, jeopardizing sexual relationship with his wife. So his self esteem further diminishes. After his initial relief that his life has been extended, his mood may change as these untoward events affect him. He creeps into his own shell, his regression compounded with frustration and preoccupation with death when he sees other patients deteriorate and sometimes die. Even if he becomes stabilized, the stresses of dialysis pre-empts a truly independant normal life. He suppresses his anxiety, humiliation and loneliness and not infrequently his anger. He could be helped by counselling and psycho therapy but in most dialysis units, there is no provision for them.

The staff may so empathize with the trials and tribulations of the patient that work becomes an intolerable chore. Objectivity is lost and the staff member asks for a transfer to escape the increasing distaste of the job. A.W. Gouldner in his book 'For Sociology' (Pelican 1975), has the view that "The concept of objectivity has commonly projected an image of the scientist as linked to a higher realm, as possessed of a God-like penetration into things as serenely above human frailities and distorting passions or as possessed of a priest-like impartiality."

Medical scientists who deal with fragile human situations are also human, subject to the impact of emotional forces on their minds. Having to contend with financial restraints as well as the social pathology of dialysis, the discouraged doctor joins the ranks of the cynics and justifies his lack of action: "It is cheaper to let them die." On the other hand, dialysis technology wears another mask - a huge modern commercial enterprise has been built up over dialysis and becomes more entreprenial than medical in objective.

Haemodialysis in many ways is still a crude unphysiological process which intermittently and inadequately tries to imitate the normal kidney which performs the following functions continously:— (i) control electrolytes (ii) control water balance (iii) remove waste (iv) produce and degrade hormones (v) participate in protein anabolism and catabolism. Present haemodialysis techniques produce undesirable side effects such as:— (i) Retention of toxins, small and large (ii) Depletion of useful molecules (iii) Unphysiological intermittent cycling of body wastes, chemistries and osmolality (iv) Destruction of blood cells (11). During the procedure, patients suffer from hypotension, hypertension, cramps, nausea, vomitting and headache. Approximately 60% die of cardiovascular complications, over 10% of infections. Dialysis dementia probably due to aluminium toxicity and dialysis encephalopathy, osteomalacia secondary to hyperparathyroidism (osteitis fibrosa), and tertiary hyperparathyroidism have been reported.

Because homeostasis fluctuates and is never constant, the patient in ESRD, however well dialysed somehow perceives he is chronicaly ill. To avoid oscillations in body chemistry, the wearable continuously operating kidney (WAK) has been developed but there are several obstacles to this technique: lack of good urea absorbers, need for continuous anticoagulation and lack of vascular access for permanent implantation. Therefore CAPD, (continuous ambulatory peritoneal dialysis) which offers continuous dialysis without cycling of body chemistries, seems a logical development. The advantages are:— freedom from the machine, less sickness and weight gain. However the weight gain from the daily absorption of 100 gm carbohydrates is associated with triglyceridemia and the promotion of vascular disease. Its great advantage is its simplicity and adaptability for self care home dialysis. Can an elderly patient cope with the discipline of CAPD? In many countries CAPD seems suitable for elderly patients. If the connecting tubing is changed every 4 weeks under sterile conditions by a nurse instead of weekly by the patient, the dressing changed every 3 to 7 days instead of daily, dialysis is performed 7 days without an adaptor, the incidence of peritonitis it is claimed can be lowered to an average of one episode every 10 months. By October 1979, the proportion of dialysis patients on CAPD was nearly 20% in Canada (12). However the patient must be highly motivated to avoid short cuts in the procedure or altering the order. The staff should be able to identify the patients who do not have the enthusiasm or intensity of attention.

Dialysis technology employing advances in engineering design and electronics, constantly upgrades machines and delivery systems until we now have a wide variety of complex new dialyzers to choose from. So the industry is left with the older models which have been traded in or unsaleable in the West. Hopefully these machines, unused or refurbished could find an outlet in the less developed countries. What are the hazards of using these outmoded machines? Frequent breakdowns and difficulty of getting spares may preclude a large scale purchase but they could serve as an interim or ancillary measure. The 1980 Brandt Report states that countries have a per capita income of less than US$200 have a combined population of 1,215 million. It is inconceivable that such countries including areas in South and East Asia could provide a chronic dialysis programme. For these countries we need a breakthrough in technology to produce a low cost dialysis machine and equipment that are easily produced in a developing country and can be operated at low cost in rural districts by semi literate village health workers. For health should not be the prerogative of the well to do urban dweller who after all occupies only 20% of Asia.

COST OF DIALYSIS

In USA the annual cost of haemodialysis varies from US$24,000 to US$30,000 for centre dialysis and $6,000 to $24,000 for home dialysis. CAPD costs also vary from $5,000 to $14,000, while cadaveric transplantation costs from $14,000 to $23,400, live donor transplantation cost approximately $20,000 US. In India transplantation could cost as low as 20,000 rupees ($2,500) (2). When dialyzer filters are reused there is remarkable savings. Allowing $10/- US to clean and process filters for the second and third reuse, there is a savings of $91 million US in reusing 5.5 million filters for 35,000 patients. The experience in Singapore is based on reuse so that for the 15 patients on home dialysis, the average cost is estimated at US$6,000 per patient annually. For the self-dependency dialysis unit which serves 20 patients in one morning shift, the savings come from using Kiil boards, the spouses helping in the preparation, etc, with one renal nurse in attendance and the cost is estimated at $4,000 US per year. Centre dialysis in the region should cost half of that in the States and Japan because of lower staff salaries and reuse of filters. Capital costs in centre dialysis can be reduced by using multi patient machines. There is however a point below which further savings in cost cannot be effected without loss of efficiency and danger to patients' lives.

CAPD costs more than home dialysis because of the high cost of imported dialysate. Without the technology to manufacture the special bags, filling and sterilizing them, developing countries would find it difficult to reduce the cost of maintenance below $6,000 US. However if several countries could join in bulk purchases and through voluntary bodies such as the National Kidney Foundation, supply them to the patients directly there would be significant reduction of costs.

THE QUALITY OF LIFE CONCEPT

As physicians we must never forget that we are not technicians even though dialysis requires a high technology that we should know something of. Our job is not to tinker with a mechanism but to make a person as whole as possible.

In the region, chronic dialysis is not readily available in many places. Strict triage has to be practised for the few places available each year on the dialysis programme. However a principle has to be established in the management of ESRD. If mere prolongation of life is not the objective then the goal in ESRD must be an acceptable quality of life through a comprehensive management plan covering physical, social and psychological functions.

If the quality of life concept is adopted as the ethos of chronic dialysis, the decision making process must involve the patient and his family besides the medical team. The evaluation work up by the inter disciplinary team must include assessment by the physician, nurse, medical social worker and psychologist. The exclusion of multi system disease and undesirable traits that militate against continued dialysis, the availability of family and other social support and the potential for live and cadaveric donor transplantation are basic assumptions that underlie this approach. Success in dialysis treatment, whether it is haemodialysis at the centre, home, self care or CAPD all require effort to identify the right candidate for the particular modality of treatment. Certain characteristics of the patients and their environments may be considered risk factors. Motivation and mental acuity to a certain degree are certainly prerequisites.

For those who have achieved a quality of life on chronic dialysis, their life styles, purpose in life and physical functioning have not significantly changed. For those who failed to do so, quality of life is poor by all standards. In this latter category are patients who have been brought into the programme without careful screening. They may exhibit all or most of the following undesirable features namely, total dependance on family, medical personnel and social agencies for emotional, physical and financial support. Their rehabilitation potential is meagre and self care capability negligible. Prognosis for life expectancy is poor. The family is increasingly disturbed by the patient's total dependency on them and obvious inability to help himself. At this stage the physician must address himself the question - "Am I merely prolonging life or delaying death?" Before such a patient is put on chronic dialysis, the medical team must be sure that they are all agreed on their appraisal of the patient. If he is scored below the average, the team could with good conscience recommend that he is managed conservatively with diet and medication and permitted to die naturally of kidney failure. But this decision cannot be taken unilaterally. The patient and his family, and the family physician should have a session with the physician and medical social worker. The patient and family have to make the final decision. It is made clear that conservative management does not imply that the patient is not cared for. The choice is a result of exercising their right of self determination. Terminal care support should be available in such cases. If the patient and family do not agree with the decision of the medical team they would have to accept full responsibility if they opt for dialysis or other non conservative modes of treatment. In such cases, many of the anticipated complications medical, psychological or social would arise. When that happens the family, even the patient himself, would want to discontinue dialysis. The key principle of this quality of life approach is that a patient and his family make the alternative choice to chronic dialysis, that is, death with dignity. And the profession has not compromised with standards or ethics, because the doctor will continue to manage the patient conservatively with all resources and skill at his disposal. This is vastly different from the attitude of doing nothing.

CONCLUSION

What are the lessons that we in our region can learn at the end of two decades of managing ESRD? In the first place we should acknowledge the failure of the medical profession as a whole to always translate conviction into action in meeting this human problem. We have hesitated, temporized and compromised although we knew and the patient knew that there was only 3 choices: chronic dialysis, transplantation and death. By admitting that we have not done what should have been done, spurs us to greater effort to redeem our failure. Had it been a purely economic situation, it is almost certain that economists will take a hard headed approach. Since ESRD is categorised as a clinical problem, the non clinical person whether he be administrator or politician, tends to avoid the issue. The figures involved are not catastrophic as with the boat people and refugee problem.

The renal physician finds that he cannot pass the responsibility to the economist or social scientist. What is he to do then? He must enlist the best possible help he can find. This takes me to the second point. The doctors and the community must come together if the climate of response is to change in favour of a positive approach to ESRD. In practical terms it leads to the founding of a National Kidney Foundation so that a group of concerned persons and professionals could study the issues and make commitments to solve them. We have found it does not need to have a large group to make representation to the private sector and governmental authorities. We have been surprised that the NKF has an enormous amount of goodwill not only from the press but also philantropists and Foundations if the case is rightly presented. But a core of dedicated individuals is mandatory to success.

Thirdly, while accepting the limitation of health care resources, we must not be swayed overly by financial constraints nor be intimidated by formidable difficulties and adapt a negative attitude. Cynicism more than criticism creates a nihilistic attitude. "Why not let them die? We cannot afford dialysis and transplantation, both of which produce problems and their own pathology. We have enough problems already." But like Pilate, washing one's hands does not remove the blot on the uneasy conscience when we know that much can be done. We can begin to treat ESRD better conservatively, and establish dialysis in a small way on very strict criteria. This was our experience in Singapore. We began with one machine in 1961, a one bed dialysis unit in 1964 which grew to 4 beds and by 1968 had transferred to an 8 bed unit housed in a disused attic. Renal transplantation started in 1971. A 10 bed self-care unit was established in 1975. Currently the National Kidney Foundation is completing its own 24 bed dialysis centre at the Kwong Wai Shiu Hospital and has a home dialysis and CAPD programme.

Fourthly, it is good medicine not to treat the end stage but the initial stage of any problem. There would be fewer cases of ESRD if an active preventive programme has resolutely tackled the early beginnings of renal disease and conserved the function of those in early failure. Thus the public must be made aware of the early signs and symptoms through the media. The medical profession should be alerted to the iatrogenic causes of toxic and immunological varieties of nephrites. The list of nephrotoxic drugs increases each year and it is most important to identify and remove them. Anagesics and antibiotics such as the aminoglycosides, colistin, amphotericin B are well known toxic drugs but methicillin, rifampicin, phenindion can cause acute interstitial nephritis and heavy metals, mercury and gold and D penicillamine can cause an extra-membranous glomerulonephritis. Renal infection could proceed to chronic renal disease and failure if not eradicated. It is time to stress aetiological treatment of toxic, infective and immunological causes of renal disease and thus avert ESRD.

Fifthly, we must explore other options. Can we bind urea and its percursors outside the renal tract. Even if this is incomplete as for example by giving 150 g of oxycellusose orally, dialysis time can be shortened. With the rich experience of herbal remedies in the East, is it possible that we have not sufficiently explored their use in eliminating nitrogenous products for the alimentary canal and skin? For example Dr. Yatzidis of Greece, has used locust bean gum derived from the seed of the Ceratonica Siliqua tree as a potent oral Sorbent of most uraemic substances. It is considered harmless, is well tolerated over months and reduces high blood pressure by the third week and the frequency of dialysis (13).

Lastly, what is the remedy we can prescribe for ourselves? Between deliberate budgetary policies of restriction of funds for health care and the individual responsibility of appropriate action to save a life, there seem to be a chasm which cannot be bridged. Committees in general cannot produce innovative changes but individuals can and do. Some of the most important people concerned in ESRD are volunteers who cannot understand the barriers that are placed in the way of local initiative. Often they compare this infinitesimal slow process with the rapid advances in their own field of work and often as not they abandon their effort. What we need obviously is a comprehensive and intergrated strategy involving the relevant machinery of government and committed and responsible citizens who can together direct the achievement of the greatest effort from the existing and new resources. Our greatest resource is the will of the people.

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