
Chapter 16

Memories of Changes in Renal Care over Three Decades – the Human Perspective on Registry Statistics

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Key Words

Childcare · Home dialysis · Kidney · Lifestyle · Patient care · Renal replacement therapy · Transplantation

Summary

- These are personal reminiscences of 35 years of renal replacement therapy, augmented by recollections of other patients and staff from these early days.
- There have been major changes in the possibilities of care for children with established renal failure.
- Attitudes towards care and lifestyle possibilities have become more liberal for patients.
- Much has changed, mainly for the better and some old ideas have come back into fashion.
- Long-term patients have been through very difficult experiences and might have strongly formed opinions about their treatment as a result: perhaps staff should listen to these patients and learn from their wealth of experience.

Introduction

Having received a kidney transplant as a child over 30 years ago, following over two years of conservative treatment and two years of haemodialysis, I decided to look back at how the treatment and care of patients with renal failure had changed since those times.

Method

Patients and staff involved with renal care in the late 1970's and early 1980's were contacted and asked to give recollections of how diet, dialysis and transplants were managed then and these were compared with how things are done nowadays. This allowed not only the medical and surgical side of renal care to be examined but the psycho-social aspects as well.

Results

Diet

The lack of sodium, potassium and protein in the Giovanetti diet caused it to be bland and unpalatable. Diet sheets gave long lists of restricted food and without supplements led to stunted growth and renal rickets in children, osteomalacea in adults and malnutrition in both groups. After my transplant at the age of 12½ years, my ideal weight was increased to 22.5 kg and my height was about 1.17 m. Development of supplements, especially 1- α and water soluble vitamins, along with the de-restriction of protein, have now mainly consigned these effects to history: in fact renal physicians are now finding a problem as their patients are often over weight or even obese.

Children

Children were rarely accepted onto renal programmes, with hospitals telling parents to 'take your child home and let them die in peace!' In forward thinking hospitals where a few children were accepted, children and adults were cared for together on the same ward. I was the only child on my shift and prior to dialysis I was taken on my own ward round to say 'hello!' to everyone else, but as the ward only housed around 10 to 12 patients it did not take that long. It was my job to talk to new patients, who were often placed in the bay beside mine, telling them it was not as bad as it seemed – sometimes I even let them borrow a teddy!

Paediatric nephrology was a thing of the future and those children who were accepted were treated as 'small adults' with treatment defined for adult use being roughly adjusted for children. Nowadays children have their own services with specialty staff, wards and even hospitals, allowing treatment to be precisely tailored for their size, age and intellect.

Transition from paediatric to adult care is now seen as a major hurdle to be overcome with young adults being reluctant to start taking responsibility for their own health. With care being continuously in the adult system there was no transition and children were encouraged from an early age to be involved with their own care and take responsibility in the same way as the adults treated alongside them.

Dialysis

Haemodialysis was the only method of regular dialysis available, using mainly Kiil Kidneys (figures 16.1a, 16.1b) which had to be stripped down, cleaned and rebuilt each time between dialysis. This was a long process and if when tested the machine failed, the whole process had to start again. When an operative was relatively new to the machine, failure would occur about 10–15% of the time reducing to approximately 5% with experience. Although the kidneys used now (figure 16.2) are far smaller, disposable and more efficient than the Kiil kidney, the average time spent on haemodialysis is still the same at 4 hours, three times a week. As a tiny child, due to small blood volume, I only dialysed on half a kidney with one 'layer' being clamped off and dialysed for 3 hours, three times a week.

Arterio-venous (AV) fistulas were still a fairly new development when I started dialysis in 1978, but, as is still the case, they were recognised as the preferred access method. Patients were taught how to put the needles in themselves as early as possible, allowing them to take more control of their own treatment, which is only just starting again. Today several other forms of access are used when the fistulas do not work or are not feasible, including neck lines (figure 16.3) and AV grafts, but in the 1970's and 80's Schribner shunts (figures 16.4, 16.5) were used as a temporary measure until fistulas were established. The advantages of the simplified shunt included a good flow of blood, without the need for 'needling' but the disadvantages were that the shunts tended to clot. They were declotted by streptokinase being injected into the shunt which extended the life of the shunt, but was extremely painful as the clot was broken down by the enzyme. The shunts

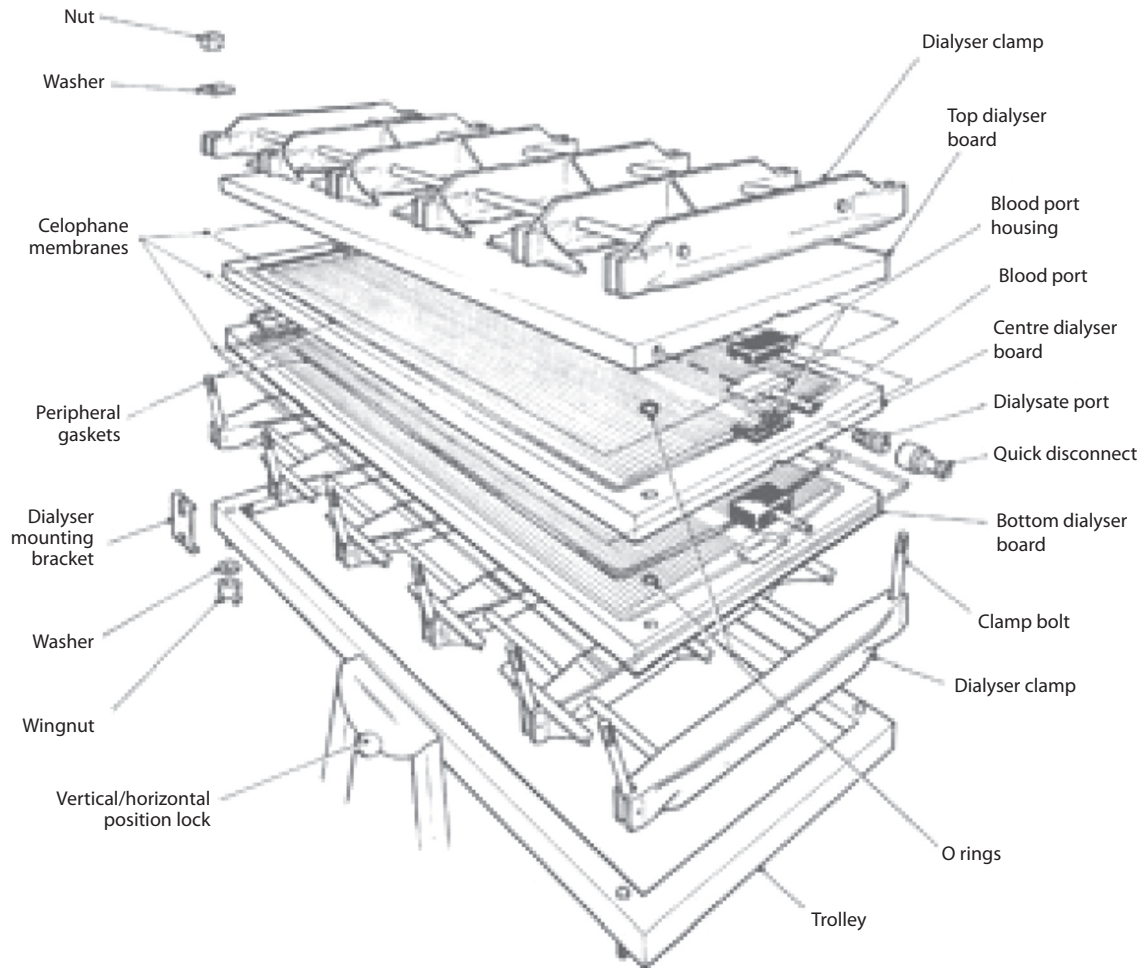


Fig. 16.1a. 1980: Schematic construction of a Kiil dialyser according to the original English drawings



Fig. 16.1b. 1980: Reusable Kiil kidney



Fig. 16.2. 2010: Disposable kidney



Fig. 16.3. Portacath neck line

also got infected, fell out although they were stitched in and some were pulled out by patients. They did not really provide a permanent access and when required for a longer period often had to be re-sited.

Peritoneal dialysis (PD) was used only as an emergency procedure but with no soft in-dwelling catheters was extremely painful, with each session lasting 24 hours. Insertion of a new stiff catheter each time PD was required caused a major difficulty as the peritoneum could become attached to the puncture site rendering further puncture almost impossible. The whole procedure often left both physical and mental scars on patients, especially children, who endured this treatment.

Various types of peritoneal dialysis are now available and used on a regular basis. Soft in-dwelling catheters have made it patient friendly and can now be successfully used by patients who perceive an increased freedom over haemodialysis.

Dialysis centres were few and far between and access to dialysis was very restricted. Patients therefore were encouraged to learn how to dialyse themselves and partners, parents, relatives were also taught so that patients could go onto home dialysis. This went out of fashion when more satellite dialysis units opened but recently interest in it has grown and more people are being encouraged to opt for this form of treatment.

Transplantation

In the 1970's transplantation was in its infancy and restricted to kidneys. A hospital stay started with 7–10 days barrier nursing, followed even in uncomplicated transplants by several more weeks or months in hospital.



Fig. 16.4. Scribner shunt

Patients nowadays are often out and home in 8 days or less.

Kidney donation from friends and even altruistic donors is now common place but used to be restricted to close relatives and they were subjected to large incisions and lengthy recovery periods, a far cry from the laparoscopic methods often now used.

Cadaveric donation was from heart beating, brain stem dead donors only and they had to be both young and healthy. With the increased number of patients requiring transplants and the number of heart beating donors declining, a wider range of donors are used. The use of extended criteria donors has seen non-heart beating donors being used and the average age of a donor has increased by 15 years in the last 15 years. To utilise these donors, dual and en bloc transplants of kidneys have been used.

Although kidney matching only consisted of HLA-A and -B tissue type plus blood group, matching was as close as possible. Today tissue typing includes HLA-C, -DR, -DP and -DQ as well as antibody screening of all listed patients, however due to the major advancements in techniques and immunosuppressive drugs, donors and recipients do not always have to be as closely matched with transplants possible across blood groups.

In the 1970's and 1980's kidney transplants were optimistically expected to last from 5 to 10 years, whereas now the estimated half life of a cadaveric transplant is 10 to 12 years and living donors 15 to 20 years with a few people around who have had their transplants for over 40 years and are still on the 'old' drug regime.

In 1980 immunosuppression was restricted to Azathioprine and steroids, but in the later 1980's Cyclosporine started to be used widely. More recently Cyclosporine is often replaced by Tacrolimus and Azathioprine by Mycophenolate: steroids are used in smaller doses and are either avoided or rapidly weaned in most cases. The immunosuppressive regime changes have coincided with increased graft survival.

With no transplant co-ordinators in the 1970's and 1980's, transplants were allocated by nephrologists selecting the patient and surgeons liaising with UKTS, retrieving kidneys, arranging surgery and organising transport for those kidneys to be exported, as well as carrying out the transplants. Now there are transplant co-ordinators who are specialised for cadaveric donor families, live donors and recipients.

Miscellaneous

Specialised staff consisted of medics, surgeons, nurses and dieticians. The multi-disciplinary team now available allows for a holistic care approach for both patients and their families.

One treat many patients looked forward to during their first half of haemodialysis was the consumption of food which was otherwise forbidden! The smell of bacon sandwiches and the sight of patients eating chocolate in the first hour or so of dialysis were not unusual, with patients making the most of this precious time.

Strict infection control policies followed several outbreaks of hepatitis B. One of the worst was in Edinburgh where about twenty patients died as well as four members of staff. There were other outbreaks in the UK and abroad. At that time the virus had not been identified and was referred to as the Australia Antigen. Access to both the dialysis and the transplant wards was through a locked door and all visitors had to put on a white surgical gown over their outdoor clothes. Nowadays there is free access with appropriate hand hygiene.

Low haemoglobin was normal, Hb 5 g/dl not being rare, as there was no EPO or ESA then, so patients, being used to it, were tired but had to cope. Where treatment was given, it was in the form of iron or a blood transfusion, both of which could cause problems. Oral or IV iron led to the risk of iron overload and blood transfusion was not as safe as it is today plus there was the risk of viral infection such as Hepatitis B and C.

Holidays whilst on dialysis were rare, as infection risks especially abroad, were deemed to be too great, plus with the very limited number of dialysis spaces there was not the room on dialysis units to take others on. Those on home dialysis could occasionally take on holiday a portable, disposable machine which was the precursor of the disposable kidneys used today, but this form of dialysis was in its infancy. Holidays could sometimes be taken by using holiday homes in the local region which had been set up with a specialised dialysis room, but

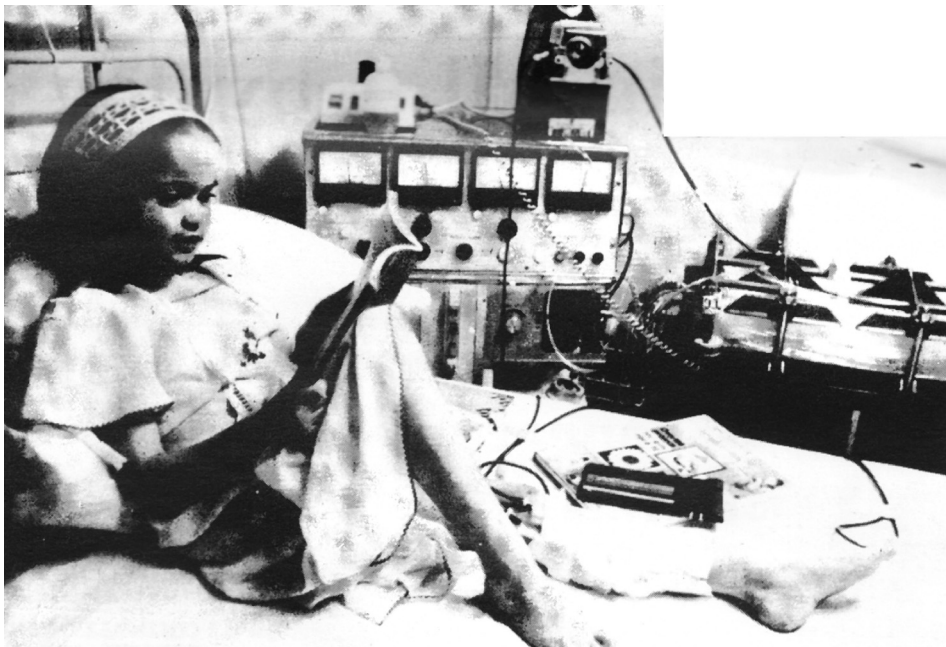


Fig. 16.5. Image of patient dialysing using a Scribner Shunt. Old style dialysis machine, pump and Kiil Kidney can also be seen

again only if you were on home dialysis and these holiday homes were few and far between. Today access to dialysis away from your local hospital is easier to organise in this country and can sometimes be organised abroad, but with special care taken where there is a high indigenous rate of hepatitis. The different forms of peritoneal dialysis also mean that travel and holidays can be more easily organised.

Patients remember supporting each other after results were posted on the ward for all to see. In those days a creatinine rise was very serious and often ultimately fatal. With patient confidentiality nowadays, patients do not get told each others results but the camaraderie is definitely still there.

The way to show that you wished to have your organs used for transplant was by signing a kidney donor card. Over the years as it became possible for other organs to be transplanted this changed to become an organ donor card and your willingness to donate can also be

indicated on your driving licence. The donor register is a centralised database where donors can show their decision to donate and medical staff can check to see if they are signed up prior to speaking to relatives about any donation. The opt-in system that was put in place when transplantation began is still the system that is used today.

Conclusions

Much has changed, mainly for the better and some ideas, such as the use of home dialysis, have come back into fashion. Staff should remember that long-term patients have been through very difficult experiences and might have strongly formed opinions about their treatment as a result. Perhaps they should listen to these patients and learn from their wealth of experience.