

*Invited Comment***The doctor who is a patient: conflicting or complementary roles?**

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It is often said that doctors make difficult patients. Perhaps this is because the role reversal is so profound—from care giver to receiver of care. The one who is trained to restore health and maintain life, now finds his health challenged and life possibly at risk. The healthy physician develops defenses against disease in order to feel immune in the face of sickness and death [1]. When the care giver becomes a patient he or she faces an implied loss of control in a profession which prides itself on the control of illness in others. Difficulty in changing roles from doctor to patient implies that there is an incompatible duality between the role of healer and that of the recipient of care. My own experience as patient who became a doctor has shown me that this is not necessarily so.

**Formation of a patient–doctor**

I have found few problems in being both physician and patient. I find the roles in myself to be compatible, learning from both, with each imparting useful information to the other. Perhaps the significant difference in my experience, compared with that of doctors who become patients, is that I was a patient before becoming a doctor. I learned of my kidney failure in 1966 when I was taking pre-med courses in college. I had to face and deal with my sickness and potential death before I learned to heal and save the lives of others, and I have never seen my role of patient as threatening my role as doctor.

In those infant days of haemodialysis I was carrying out my own treatments in the home with my backup centre at least 1500 miles away. I was thus fully involved in the medical care including setting up the dialyser and machine, running my dialysis treatments, following a strict diet, and on occasion declotting my externalized leg catheter. At the same time I was a full-time pre-medical student. To survive I had to accommodate both roles. It could be argued that I was living with denial, expecting to go on to medical school as a dialysis patient. Nonetheless, I was accepted to medical school, learning that hard work sometimes

pays off—with a little luck. In subsequent years as a doctor I have been supportive of patients who reach for ‘impossible dreams’ realizing that where there is a will, there is a way. I have learned that the best thing one can do for such patients is remove unnecessary roadblocks that others might put in their way.

When I started medical school the job of being a patient became much easier. Although the dialysis time was longer (14 h, three times per week), I received my treatments in a hospital unit where all I had to do was show up. I also acquired the fistula which has lasted to this day. I became comfortable in my patient role as I assumed the doctor’s role. This seems also to be true, in my experience, for those few who have become doctors while dealing with a major medical illness. In medical school and post-graduate training, however, I tried to overcompensate as the doctor for also being a patient. I studied without time off for recreation to get the best grades in medical school, worked a regular house officer’s schedule during training, and willingly covered extra weekends and holidays. Just graduating alive and finding a comfortable niche for post-graduate training would have been success enough. Perhaps it is just the drive of my personality to do the best I can that has also helped me survive 32 years with ESRD. The 2 years of my post-graduate residency consisted almost entirely of dialysis and medicine, with an occasional date, usually dinner and a movie. The first 3 months as an intern I spent every other evening on-call and dialysed every off night. Subsequently, I was on-call every third night and dialysed alternating two nights in a row and one of two nights. I had to learn to operate on the medical wards with great efficiency to be able to squeeze in the dialysis schedule. I never shirked my responsibility for efficient and sufficient dialysis treatments. It was free time that had to be sacrificed. I learned that doing dialysis well allowed one to function at a level of considerable activity. If I could survive the most difficult years of my dual life then the rest should be comparatively easy. And so it has been.

**What the patient has taught the doctor**

I have viewed my own medical experience with resigned acceptance more than with the anger and sadness that

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doctors who become patients often write about [2]. Lessons from these experiences of being a patient I have tried to apply as a doctor. One involves the personal value of time. Patients are annoyed when they have to wait long to see doctors, who often consider their time to be more important than the patients'. Hospital clinic scheduling usually ensures long waits, but few doctors pay any attention. I am sensitive to this because monthly clinic visits while I was a predialysis student forced me to skip a laboratory class which I would have to then find the extra time to make up. While I arrived on time at the clinic I invariably waited at least 2 h to be seen—or rather to be interviewed by a different medical student each month, as I later realized. My attendance was a benefit to the teaching programme but a waste of my time, since in those days they had no effective therapy to offer me. When I am delayed in seeing a patient I attempt to apologize for the delay, and I try to make sure whenever possible that patients are not being scheduled to wait. I feel that their time, whatever they do with it, is valuable to them. A small word of apology is considered by most patients to be adequate compensation for inevitable delays.

Another lesson learned was to listen to the patient's explanation for an adverse event because my obvious conclusion could be wrong. Early in my dialysis course I was accused of eating too much salt although I was sticking to a rigidly low protein, low salt diet, even though it was unpalatable. Meat portions were weighed to the ounce, and food was made without salt. Every day for lunch I ate a meal of pasta with low salt butter and raw cabbage with a low-salt mayonnaise dressing. This problem was solved after a short investigation by the machine technician who took me at my word and looked for another answer. As it turned out the water used for dialysis was very hard and was treated with a water softener giving the dialysate water a high sodium concentration. Addition of a deionizer solved the problem.

I have learned that the most important cause for noncompliance with a prescribed treatment is really a clash of agendas. Care givers may have a superb medical plan for the patient but if the patient has a conflicting plan, noncompliance will inevitably be the result. Thus, it is important to elucidate the patient's motivation for acting contrarily and deal with it sensitively. When I began dialysis, aluminum containing phosphate binders were only available in liquid or in the form of large tablets. Both tasted like chalk and were firmly constipating. This, combined with an insufficient appreciation of the long-term complications of hyperphosphataemia, led to the only normal reaction possible—not taking the binders. (It took another dialysis patient, working for a pharmaceutical company, to have the chalky aluminum salt put in a palatable capsule.) It still constipated but it could be swallowed without inducing nausea. Personal experiments with over-the-counter laxatives alleviated the constipation. My agenda was for comfort, negating any attempt to keep the phosphate under control, because there were no immediate adverse symptoms

for non-compliance. I appreciate the reasons patients have for not taking medications or following a medical regimen. Fear, denial, cost and side effects of medications, different health beliefs, all can be dealt with given time, patience, a willingness to understand and suitable efforts to bypass hurdles.

In attending solely to laboratory values, one can draw mistaken conclusions about patient's intentions. The high blood sodium and phosphate levels, in combination with an event where my inadequately taped shunt came apart during overnight dialysis at home while I was asleep, led my doctor to the 'obvious' conclusion that I was suicidal, prompting a psychiatric referral. The weekly, 50-min, one-way conversations were not bad but did take up time I would rather be studying to get grades for medical school. I had accepted my life with dialysis as a necessary inconvenience in my desire to get to medical school. I had not yet been told it was not possible to go to medical school as a dialysis patient, and so had no reason to be severely depressed. I have found it useful to listen to what the patient is saying—really listen. It takes time which is too often in short supply for the doctor, but what the patient is saying quite often leads to a solution to a problem. Many patients have not learned to express themselves well in medical jargon. There is always a reason for which the (non-psychotic) patient does what may appear abnormal. It is a challenge to figure out why.

Through my experience as a patient I have learned to be aware of the influence of family and friends. Love and support are necessary when one has to deal with life's complications. Fearful for my uncertain future, my family and friends withdrew from me emotionally. In the early years I felt much alone. As a physician I find it important to keep the family informed. Using their support for the patient when appropriate can positively influence outcomes. The life I have lead has been made possible by the unstinting love and steadfast support of my wife and the renewed attention of my family.

### **How the doctor has assisted the patient**

During my training in medical school I began to learn that I should try to make normal what was considered abnormal. Hypertension was a problem I had only during my predialysis illness and with a transplant. Dialysis quickly brought the blood pressure under control both in the beginning and after the transplant failed. As long as I kept my body without excess fluid I did not require medications for pressure control. Incidentally, it was not until my transplant, 25 years after starting dialysis, that I ever had to take an antihypertensive medication. It was not a pleasant experience. The knowledge I acquired in learning to be a doctor gave me a better understanding of the dangers of uncontrolled blood pressure. It broke through any denial of adverse consequences I might have held as a patient alone. Eventually after two

subtotal parathyroidectomies I developed the same concern for normalizing Ca and P levels.

My innate conservatism as a patient has been aided by my medical knowledge in making a choice for or against medical 'advances' and 'breakthroughs'. My goal has been to strive for length of life of acceptable quality, even though compromises may have to be made with the latter. Opting for an AV fistula over the external shunt or graft was obvious. One did not have to be a doctor to see the advantage. My 32-year survival derives unequivocally from having the same fistula for 30 years. I alone have placed the needles and to do likewise is the best advice I give patients. When I began dialysis, treatment length was 10 h overnight for three weekly sessions with the Kiil dialyser. When beginning medical school it was increased to 14 h three times per week. Reducing the therapy time to 6 h with a coil dialyser seemed at first a great advance. The price was inadequate dialysis. I learned that quality is more important than convenience and that one must expend the necessary time and effort to achieve it. Large hollow fiber dialysers resolved the time-adequacy dilemma, then even these became smaller to meet cost-cutting demands. As a privileged patient with a firm sense of proper dialysis I was able to avoid the dangers of dialysis inadequacy this time around. To my mind in training it seemed logical that more dialysis was better since only about 15% of kidney excretory function was being replaced. Sadly during the 1970s and early 1980s it was not a widely applied experience.

As a patient I look with concern upon financial compromises that could affect my health care. I view reuse of standard sized dialysers that cost under \$15.00 as purely for profit enhancement with minimal benefit for patients and the potential for considerable harm. Everything I know as a physician, combined with awareness of the fallibility of those individuals reprocessing the dialysers only heightens my anxiety. Peritoneal dialysis is another therapeutic alternative I would preferably leave alone. Advantages for this therapy over haemodialysis are clear; however, the disadvantages are more impressive. My goal for a long, medically minimally-complicated life would not be well served by PD. My experience as a physician treating patients with peritonitis reinforces this impression.

Kidney transplantation is the simple answer for the patient with ESRD. I have heard this almost from the time I began with dialysis. It is, but only if it works well from the beginning and offers only minimal complications. I rarely try something new until after it is well proven or of obvious advantage. In my short medical experience I have seen too many medical therapies fail after the first blush of success. Nevertheless, after 25 years of dialysis and several years of observed experience with cyclosporin I decided to see what all this hoopla about transplant was about. The kidney I received did not work for 42 days, then opened up with a slowly increasing amount of urine. It was like a miracle. Food tasted better and could be

eaten with less guilt, while travel was easier and eagerly looked forward to.

Being a doctor and nephrologist created a potential problem with the kidney transplant. I always managed my dialysis with advice and a careful perusal of the literature. Viewing transplant management as a more tenuous skill I did not want to manage my own graft. Responsibility for making a wrong call on immunosuppression was perceived by me as onerous. Once the genie of rejection was out of the bottle it would be very hard to put it back in. Treatments were limited since I am hepatitis C+ and not eager for a liver transplant. It was not easy to find a doctor willing to take full control. Experience had shown that even though patient I could function well as a doctor, as a transplanted patient it was difficult to find another doctor to take charge.

After 4 years of satisfaction the problems came: hypertension, antihypertensives, fluid retention, gout, and anaemia. I was getting more shortness of breath which could not be relieved by diuretics and the hypertension would not give way to a variety of antihypertensives. My training and the skills of my doctors seemed useless when facing the onslaught of chronic transplant rejection. This experience only reinforced the belief that despite the miracle of dialysis and transplantation and all the advances associated with these therapies there were still limits.

The end of the transplant was not greeted with alarm but with regret that the anxiety for travel has returned and evenings are lost to dialysis. The patient and doctor are agreed that future attempts at transplantation will be approached cautiously, ideally with better and less immunosuppression. After a year and 6 months more I have almost fully recovered my health. I am gaining muscle weight steadily, losing the amyloid deposits in my shoulders through weekly massage therapy, working a full day and week, and enjoying food better than anytime in the past while on dialysis. I have a renewed impression of the benefits of quality dialysis.

I have found that life for length with ESRD is best lived in moderation. This is a lesson learned as a patient before becoming a doctor. Excess of either emotion or activity are not compatible with long life if one has a chronic medical condition. This invariably has a stunting effect on ones talents and the practice of 'nothing in excess' leads invariably to a life of some constriction. Choices have to be carefully weighed and at times compromises made. Nonetheless one can have a life in which a reasonable level of happiness and satisfaction can be found. My life as a patient has been positively influenced by also being a doctor. The reverse is also true.

## References

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