

This is a resident case log of a patient encounter in which an "Aware Medicine topic" was central.

## Dialysis as a Means to an End?

It is ironic that one of my most profound continuity relationships in medicine thus far involved the relatively brief in-patient care of a hospitalized patient. I first admitted this 63y/o gentleman to the service for acute on chronic renal failure in the setting of end stage alcoholic cirrhosis. From our first meeting, it was apparent that this was an intelligent, independent-minded man with a clever sense of humor and a very straightforward, unrestrained demeanor. Although he seemed quite aware of the implications of his terminal diagnosis of cirrhosis, he was frequently non-compliant with his lactulose and other meds, and he did continue to drink. He once explained to me: "I am lucky to have lived as long as I have. I have been abusing my body all my life, and I knew it was going to catch up with me. I know I've only got a few months probably, so why not enjoy them the way I want?" This was a difficult question to answer, but continued to arise in a symbolic way. He had also already declared DNR status, though he was not on hospice care.

In terms of the present admission, a combination of diuretics, diarrhea, and third-spacing had hit his kidney hard and his creatinine had risen fourfold. As the days passed and things did not improve, we began discussions about dialysis. The renal consultant, or rather the resident and fellow sent on his behalf, were very clear with him that dialysis would likely be permanent. Unfortunately, they failed to appreciate his sense of humor and idiosyncrasies, and when faced with the cold prospect of lifelong dialysis with no counseling or sensitive education, he decided that he would rather pass away uremic. Over the following days, we met for an hour or two per day, and developed also quite a friendship. While on call I would stop by during free moments, and we would sit and discuss philosophy and beliefs. He expressed his need to feel that he had some control over his body and self in order to remain a free soul. He also confessed that he saw his present state of disease, in a vague way, as punishment for a dissolute life. Through discussion, he was, however, able to see that in accord with his own core values, he had been an essentially "good" person. And he eventually came to see a decision to participate in his own care, such as taking his meds, following dietary advice, and limiting his drinking, as a symbolic gesture of affirming life, and opting for quality of life, rather than merely an exercise in futility and self-denial.

In terms of dialysis, we had reached the following conclusion. He would accept a tunneled catheter to start dialysis for a trial of one month, at which point he would either have recovered sufficient renal function, which was unlikely but possible, or he would at least see if this is something he could adjust to long term. On accepting this proposal, he stated that his experience with our team, including the family medicine attendings, had indeed opened his eyes to the concept of healthy spiritual life even in the presence of disease. The family medicine attendings also continued to support his autonomy in decision-making and this further empowered him. One conflict, however, arose repeatedly, complicating his care. His outpatient experiences with his specialists had already soured him to consultants, and each day the renal team would visit his room he would change his mind about accepting dialysis. This created a fair amount of confusion between his various providers, and each noon I would have to phone the renal team and resolve the conflicting information.

By the time of his discharge, he was stabilized but still in need of dialysis, not emergently but likely within a few short weeks. The parting was quite emotional, and gave me his email address. His one desire was to take me for a ride in his new convertible and then have a barbeque party and enjoy a cold beer together. This occasioned ambivalent feelings for me, as the offer was quite tempting on the



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one hand, minus the alcohol which ethically I could not directly support. It also reminded me of the older shamanistic model of healing, where the healer does go out into the community and the patient's home to establish a therapeutic relationship on multiple levels of being. On the other hand, accepting the offer would be in some ways contrary to my training, which implies a distancing of oneself from the patient (eg empathy, not sympathy), and clear personal/professional boundaries.

In the end, I planned on email contact and support, possibly with public social visits, but I never had to actually decide on the latter. Within a short time he was hospitalized again for hepatic encephalopathy and worsening renal failure, and discharged on hospice care without dialysis. His primary physician and the in-patient team kept me current with his care, and after his second discharge he contacted me via email to let me know he was home and wanted to talk. Within days, and before I had the chance to respond, he had passed away with comfort care at home.

As I reflect back on this case, it continues to raise several important issues for me. One is that although the primary care system may be broken, and one cannot always address the non-physical aspects of patient care in 10 minute slots, even in the context of hospital rounding one can reach out to a patient in this way and make a difference. Another is the importance of having a trusting and empowering relationship with a patient, one which is additionally based on understanding the patient's beliefs and respecting his/her autonomy. The failure to achieve this was reflected in the patient making the opposite life/death decision with two different sets of providers. I do wonder if and how the patient's outcome may have been different had he been expediently started on dialysis. Perhaps not much is the likely answer. Nonetheless, it was the journey of self-awakening and defining what is sacred that mattered most in his last weeks, and undertaking this journey with a patient is both intimidating and very rewarding, and is sure to blur the boundaries of the current definition of physician as healer.