

The Fight in renal replacement therapy. Let's go for the fourth kidney transplant

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Abstract

Patients with chronic kidney failure make dialysis a way of life, many describe the peritoneal cyclor as "your partner" at night and haemodialysis, a part-time job every other day. But most of them live thinking about changing that involuntary night life as a couple or work and return to the freedom that kidney transplantation gives you. This story recounts the constant struggle of a woman whose "rare disease", Alport syndrome, led her to receive both dialysis treatments before she was twenty. Thirty years later, even with her hearing and visual limitations, three transplants and several hospitals where she has been leaving friends, she does not lose her smile and optimism, waiting for her dream of a fourth "bionic" transplant to leave her again, on the list of unemployment of the trade of dialysis.

Key-words: Chronic Renal Insufficiency. Hemodialysis. Renal Transplantation. Alport Syndrome.

Introduction

Alport Syndrome (AS) is a hereditary disease related to X chromosome which generally affects men while women are carriers¹. As such, they generally show few symptoms attributable to the disease but, in occasions, they can present a florid form appearing as it does in men. The characteristic symptoms being neurosensory deafness of high frequency (2.000 to 8.000 Hz)³, lesions in cornea and lens², as well as haematuria, significant proteinuria, hypertension (AHT) with progression to Chronic Renal Insufficiency (CRI)³.

In this last stage of the disease, patients have to receive renal replacement therapy, making a way of life out of it, be it in peritoneal dialysis (which even being done at home and generally during night time takes about ten hours to complete exchanges)⁴, or in a hemodialysis program, in which they normally spend about four hours, three times a week, debugging their blood through a monitor.

The only way out of this is a kidney transplant. With it, as they quit their dependency on dialysis and rigorous diet, their quality of life improves as does patient's survival. It is a routine procedure but its applicability is limited by the availability of kidneys in relation to the increasing demand by needing candidates⁵. So patients live in that hope and yet they experiment the concern for transplant rejection; also strict control of immunosuppressants and constant vigilance by means of medical checks represent new challenges for the patients⁶.

This is the basis to understand the story of María, patient with AS -an uncommon pathology among women- which in her case limits visual and aural acuity and brings her to dialysis before she reaches the age of 20. After having gone through both modalities of therapy, three kidney transplantations, and while waiting for her fourth, we intend to show her experience in this autobiographical narrative in order to show positive aspects of the treatment -emphasizing the need to identify the real needs of the individual- to generate hope within realistic perspectives.

This biographical narrative was achieved by means of an in-depth interview conducted in the supervisors office in the clinic where she is currently dialyzed. By patient request, it was conducted in a day she had no scheduled dialysis so that she would be at ease and her regular dialysis session would not suffer any incidence. Adequate atmosphere was provided by avoiding noise and interruptions. Despite her hearing loss the patient is able to carry a conversation with no problem if she's spoken to in clear and frontal manner. Her participation was voluntary and confidential. The final content of the interview was verified by the patient and her identity preserved by means of a pseudonym, while the clinical centers where she is cared for are anonymized.

The interview went on for approximately one hour and was recorded for literal transcription according to the guidelines by Amezcua and cols.^{7,8}. The information has been completed with notes about the atmosphere and aspects of non-verbal language. The patient appeared calm, with a smiling attitude

except in specific situations: when referring to her mother's feelings, her eyes become emotional, as if her family's suffering affected her more than her own.

Thirteen thematic categories are described in the narrative, developing as events happened in María's life. The narrative itself might help individuals in similar situation to confront new challenges as she does, as well as to assume that an adversity is not necessarily final.

For professionals, it Will show us how our patients confront, day by day, their renal substitutive therapy so that we do not forget that there is an individual experience behind each casa.

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AUTOBIOGRAPHICAL NARRATIVE

INTRODUCTION. My family is a normal family: My father, my mother, my brother and me. My brother, healthy and younger than me. I don't have a mate but I have many friends, some have been forever and others have appeared during my illness. I live alone in a village, 12 Km from my parents' village. As I found a job in that village, I bought a house there and moved in by myself.

THE ONSET OF THE RENAL INSUFFICIENCY. I had appendicitis. When that happened there was a substitute physician in the village and he told me I was having a cholic and sent me home. I had terrible pains and after a week like that the regular physician told me it was appendicitis and sent me to the hospital. When I got there, I had a very big infection so they gave me a bog amount of antibiotics. In the final analysis they saw that creatinine was high and they sent me to the nephrologist. He told me it could be the antibiotics but in the following analytics it went worse. Later on, they did an open *biopsy* and they diagnosed the illness to me.

ALPORT'S SYNDROM. Later on, Alport's disease was diagnosed. After the first rejection my hearing went worse and the physicians asked if there were more hearing problems in my family and they started to investigate about that illness and they told me that the renal illness was because of Alport's.

In my family there was a history of deafness, I had bad hearing and my father and his two sisters as well, only none of them had renal disease. I have all three afactations, sight, hearing and kidney. Not as much earlier, but now I have trouble with far sighting. At first you think it is because of computer screens because I have always worked with them. I worked twenty-seven years as managerial personnel in a building enterprise, but later I learned that it happens also because of the disease. In my opinion this disease is both rare and dead, there is no research on it, at least I have never been treated at all so that I could improve.

Starting dialysis. The lady physician who treated me in the hospital suggested that I should start peritoneal dialysis be-

cause I was a student and it was the most doable treatment so that I wouldn't miss class as I dialyzed myself by night. So, they brought me home a *cycler* and the material and a nurse took on my training on how to do it. I seem to remember there were five cycles of two hours each. You put the liquid inside your abdomen, it stays in during permanence and then it comes out again, and that way five bags which lasts for about ten hours. At that time, I had to go to bed earlier, not when I wanted and I was very young, I had a hard time, so I asked the physician, and she always agreed, that she would let me Saturday night free. So that night I wouldn't dialyze and went out with my friends. [And emotionally, how did you experience it, young as you were?] At first it was harsh but I said "gee, I can keep living. It would have been worse if they told me, I was to die tomorrow or in a month. But no, you can go on living with this. But my mother, of course, she was elderly and she... [tears] And I would encourage her: "If it's necessary to go to the machine, you have to go", the thing is... hang in there. I think my mother had a terrible time, worse than me. It's really her who has always been by my side and still is, and helping me so much... [silence and emotion] that she could count my story as well as I do, she's lived through the same. My father and my brother kept me company less at the hospital, but they always rise to the occasion and, of course, share feelings, helping and supporting me like she does, such is my family. And then, nothing... With the machine. I showed my machine to my friends as something normal. On Saturdays we went out partying. I have always been very careful with my illness, even when I went out, I would keep watch on fluids. Maybe I'd go out and say I'd only have one beer, but I did go out with my friends. Furthermore, when I got the call for my second transplant I had been partying until high hours of the morning, it happened that way, that kind of calls is not scheduled and when they called me, giddy up, to the hospital [laughter].

FIRST TWO TRANSPLANTS. [The first transplant] It happened approximately six months after I started peritoneal dialysis. It was a very famous case, I even had TV in the hospital recording all the operation. Since I was so Young, 19 years old, they decided to do a transplant from a 45 days old baby, it was something experimental, to try if such tiny kidneys could work

for young people like me. But the physicians didn't know I had the insufficiency and also the Alport. At first, they wanted to transplant both little kidneys but one was lost at the time of the operation and they put in the other, which had immediate thrombosis and didn't work.

Then, for the second transplant they said they had chosen a good kidney. They said "we are not doing experiments anymore". It was a kidney from an 18 years old individual, very good, but after the operation it never worked well, it lowered creatinine a bit but not enough. I was in the hospital for two months and this kidney was bigger and I already got antibodies, unlike with the first one that was rejected fast and it was so small it didn't even leave a trace. But with this one they had to perform *plasmapheresis* because I was so bad, and my life was at risk. They did a biopsy to see what was going on and they saw the kidney wasn't going to survive, because sometimes it does survive with plasmapheresis, but nothing could be done in my case so I went back to peritoneal dialysis.

INTEGRITY IN FRONT OF TWO CONSECUTIVE REJECTIONS. I had lots of troubles with the second transplant, I had produced lots of antibodies and every time I was analyzed they stayed very high. Nowadays with research antibodies aren't as much of a problem but back then I spent 18 years in dialysis until the third transplant. Although I never lost hope, I had my job I liked, I think when you don't work you get more obsessed with the disease, but I worked and traveled to a city I love and in dialysis I met folks who still are my friends, whenever I go I meet them for coffee, to see them.

FROM PERITONEAL TO HAEMODIALYSIS. After the second transplant I restarted peritoneal dialysis. I remember I was in the river and the titanium plug of the catheter got lost, I tried to plug it immediately but you are outdoors with dirty hands and the *peritonitis* came, to the hospital with a stomachache you feel you die, and after that it started going badly, I had to set the bed really high so that it could drain off and finally it didn't dialyze properly and they told me I had to change. Besides, I already had the fistula set in case it'd become necessary, so they told me I had to go to the hospital three times a week, so it became worse as I couldn't do much during the day, but luckily, I searched for a job nearby and found it so I could harmonize dialysis and that job. My rhythm was Split shift when I had no dialysis, and since my dialysis was in the afternoon, at three pm, such days I'd work only the morning shift, I eat in a rush and from there to the hospital by ambulance to my other job of getting dialyzed [laughter]. The worst part was to get dialyzed on holidays, but then I thought nurses, undertakers also work holidays so finally you tell yourself it's not that bad and as years pass you care less about that.

THIRD TRANSPLANT. When I got the call for the third transplant I was working and also, we had a heavy day at work and I had initially no appetite to go to the hospital, until my boss arrived and told me "go already!" [laughter]. I went home to get my stuff ready as I knew I'd stay there for a while. The worst ambulance of the fleet came pick me up, travelling in ambulances is horrible. This one, with no AC, and then we got into a huge traffic jam. They even phoned me from the hospital: "María, where are you?". Finally, I made it there and after some words exchanged with the physician, he told me "the

kidney is for you" and he hugged me, but I wasn't all that excited about the transplant, I told him after two kidneys I didn't see it so clear [silence]. At the end they did the transplantation and all went well. From the beginning they told me creatinine was going down but I told them that I wouldn't yell victory until it went down completely. Nine days after the transplant it was my birthday so I brought bonbons and the physician told me "you can have some too". I said only one and she said "no, as many as you want". After 18 years with limited diet, I couldn't believe it.

LIFE WITHOUT DIALYSIS AND HARD RETURN. It is much better, except that the first year without dialysis is also a hard time, it's rough. I was admitted several times, medication is tough and you have to go to the hospital often until all settles down. After that it's all good, you go back to eating normally and are free of scheduling. 11 years later I had a calcium low, they stabilize it with medication, but creatinine had gone up more than normal already. Then they did a biopsy and they saw it was bad, there was a new chronic rejection so I already knew I would go back to hemodialysis. Those months have been very hard, I have been admitted many times because I was feeling bad until I had gained much weight and had to return in a rushed manner and the worst I have lived came, which was when they placed a temporary catheter because of the urgency of the dialysis. To me it is sort of a savage act, but necessary until the new *fistula* they did could be punctured, because the old one stopped three years after the transplant. They didn't remove any of the kidneys, none gave me any problem so right now I have 5 kidneys in mi body and none works [laughter].

THE WORST, WHAT'S HARDEST. The hardest, I told you, to carry a temporary catheter, but also the hardest part of dialysis is the diet, you have to suppress some foods, for instance chocolate which I love and I can't have it, only if some day I'm coming to dialysis I fix me a little chocolate for breakfast and go on to get dialyzed so I take it out that way. But you can't do it whenever you want. The other thing, liquids, you cannot drink. Those two things are the worst. Then, as I don't get dizzy, cramps I've had sporadically, I'm lucky. Because I see my mates with cramps and they have it very rough because it hurts lots. I'm fortunate, I fare well.

THE POSITIVE, LEARNING ABOUT ALL. [Silence] The easiness you acquire after such long time coming and going, speaking with physicians, the change in relationship with them. A moment comes when you think I'm going to tell this one what happens to me and stay as cool as a cucumber. You lose the fear to speak, to ask. At first you see the physicians as someone you think won't understand you and it turns out they are the ones who will help you understand better the road ahead of you. It's very important to ask and concentrate in your illness and to ask all the things that will help you, because you know you can't have chocolate, not because this physician says so, but because it harms you and you have to keep that in mind, the things that happen to you are nobody's fault, you have to know it's like that and you must assimilate it, then you'll be in the right direction.

THE NEW HOPE. A DREAM. Right now, I am at ease in dialysis, for the time being I get a free day which is wonderful [María is dialyzed twice a week as she keeps some functionality of her third transplanted kidney] and I allow myself a little whim now and then. Right now, I don't want to be called for a transplant again, I'm tired of hospital and need to disconnect and it will come when it has to and it comes well, I don't mind a year or two, right now I'm well.

So, my dream is the bionic kidney, which will last all of my life, because the others may or may not last, but as long as there isn't a bionic one, we have this other transplant which is getting better. I have noticed much change in the topic of transplants, in the first one THEY did to me, whenever something was wrong, I saw the physicians get nervous, they started to run and didn't know what to do. Now, when there is a problem, they remain calm, they know a lot more about transplants and things run better.

THE SECRET AND WHAT TO TEACH. I don't know, maybe it's the people I have around me, my family, my friends who are there to help you up if sometimes you get down. I'm sure it's that [smile.]

I would tell everyone this is an illness you can get out of, think time goes on and you keep living. Always with limitations, granted, but you are living. It is not a disease that will kill you tomorrow, in a month, in a year [silence and emotion]. To die is worse and from this you get out, one must keep it clear in mind and push forward, one has to keep walking.

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