



Autoethnographic Account of Life in a Dialysis Ward

SMARIKA AWASTHI*

Abstract: Anthropology's concern to understand the role of 'emotions' in personal and social life developed during the past few decades in response to the rejection of the thought considering humans as mechanical "information processors". Academicians and researchers have expressed their interest in understanding 'socio-cultural experiences from the perspective of the persons who live it' (Lutz & Whit, 1986).

When people from different cultural contexts come together in environments like the medical institutions, their emotions, feelings and life-meanings undergo subtle transformations especially bearing an impact on the relationships between carers or care givers and those for whom they care that is the patients. This also influences both the experience of illness and that of care giving, and also impacts the frameworks within which these roles are perceived by others. Illness behaviours are often linked to social factors, gender norms, ethnic factors, and politics, as well as differences in philosophies, cultures, and in socioeconomic status (Brown & Barrett, 2009). Patient care varies across social contexts too but most of the care takes place within families and communities and so these also remain the close groups which are impacted the most and in turn also have a profound bearing on the cure and wellness of the patient.

Looking at it distinctively from the anthropological perspective, I realised that these variations change the experience and consequences of 'care' in ways that require detailed observation and a compassionate understanding. In this paper I have attempted to present an autoethnographical account of my experiences (during the process of haemodialysis) as a means to express my

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* Address for correspondence:A3/702, Nirala Aspire, Greater Noida West, Gautam Budh Nagar, UP. E-mail: smarika.awasthi@gmail.com

thoughts and feelings on people coming to a hospital (especially the dialysis unit here). Through this I have also attempted to approach ethical and practical questions about patient care and the caregivers struggle between the enclosed walls of the hospital and the world outside where he/ she has varied other roles to play.

Keywords: Emotions, Caregiver, Autoethnography, Dialysis, Nephrology

The Realisation

Hospitals are microcosms of society, where diverse lives intersect. Here, the socio-economic boundaries that separate us blur as patients from all walks of life share rooms, meals, and stories. It is a place where vulnerability and courage coexist, where the language of suffering is universal, transcending race, creed, and status. In this autoethnographic account I seek to provide a glimpse into my personal experiences as an observer and a participant in the hospital, specifically the unique and challenging Dialysis ecosystem. My frequent encounters offer a window into the mosaic of humanity.

The moment I alighted from my car at the reception lobby of a well-renowned hospital in Noida, a frail looking woman dressed in sky blue uniform came running towards my car pushing along a wheel chair, in case I may need one. I waved my hand at her to tell her to stop, as I did not want to embarrass myself to the services of a wheelchair staff when I could walk well (or at least I thought so). Passing through the well lit corridors and a huge hall with patient attendants obediently sitting on neatly arranged rows of chairs on the sides, I reached a ward labelled Nephrology¹. Nephrology ward was just next to the canteen on the ground floor.

Life in a hospital is a labyrinthine journey, where emotions intertwine with routines, and the human spirit battles with illness, death, and hope. Each time I step through the sliding glass doors of the Nephrology unit, I enter a world filled with both despair and resilience, a place where humanity's fragility and strength are on vivid display. The moment I entered the dialysis unit, the pervasive scent of antiseptic engulfed me, a sterile reminder of the constant battle against infectious agents. The pungent odour clings to my clothes even after I have left the unit, a testament to my never-ending war with unseen enemies. It is the olfactory backdrop to every interaction, a reminder that health and illness are perpetually intertwined.

Crossing the familiar reception area, I was warmly greeted by the manager and other staff members. I walked straight towards the highly sophisticated

and accurate weighing machine laid out on the floor in one corner. My weight was recorded in the patient record files and I was asked to move to bed number 10.

Moving towards, my bed for the first of the biweekly dialysis, I routinely glanced through the people on other beds, patients and their attendants (caregivers), nurses, dialysis technicians, and the support staff (here called as GDA or general duty assistant). This is where the anthropologist in me took over the patient in me and I found myself scanning each one of them through the anthropological lens understanding the diversity of issues, the range of behaviours, perceptions, and feelings associated with those who were the caregivers and those who were the receivers. Here was my universe of research, the dialysis ward. This was my field which I was visiting so frequently from past one year and will have to keep doing so.....without any end date to it.

About the 'Field' of Study

This dialysis unit was performing haemodialysis² for approximately 15-20 patients in three shifts of four hour duration each, seven days a week. This means that approximately 60 patients received the treatment each day. These people were from diverse cultures across the globe as India also gets a number of overseas patients due to comparatively cheaper medical charges as compared to Western countries. Within a span of about six months I had come to realise that the patients who received dialysis during the same time slot as mine had changed and were not the same ones. Digging a bit deeper I realised that there were multiple reasons for this as some of the patients who were waiting for a renal transplant were successful in getting one and did not need dialysis anymore. Secondly, some of them died and thirdly, some of them discontinued the dialysis in this hospital due to financial issues. It is not easy to sustain an expensive dialysis treatment for a long period of time for anyone, so people search for cheaper alternatives. To cater to this many charitable organisations are offering zero cost or low cost dialysis and even Government owned hospitals have provisions for charging nominal fees from the patients, but these centres are really few when we look at the number of kidney patients needing dialysis in their vicinity.

Kidney disease is the sixth fastest-growing cause of mortality globally. In India haemodialysis was introduced in 1962, transplantation³ in 1971, and peritoneal dialysis⁴ (PD) in 1991 (Varughese & Abraham, 2018). The organ donation rate in India being 0.01 per cent, most families can only take their patients to the nearby dialysis centres for treatment, this also only for those

who have the means. The most common cause of death in renal dialysis patients remains infections due to the lack of clean and well equipped centres in India.

As per an article published in ETHealthworld (June 2022), every year about 2.2 lakh new patients of End Stage Renal Disease (ESRD)⁵ get added in India resulting in an additional demand of 3.4 crore dialysis every year. The situation is worsened by the fact that India has one of the lowest nephrology workforce densities worldwide, only about 2,600 nephrologists (1.9 per million population), and a constant shortage of reliable dialysis centres, nurses and trained technicians (Garg, 2022). A surprising fact about kidney disease is that it has little or no symptoms and remains undetected in the initial stages. A majority of the patients with advanced kidney disease visit the hospital only when eGFR⁶ is 15ml/min per 1.73m². This is diagnosed as the onset of CKD (Chronic Kidney Disease) when kidneys begin to deteriorate and from here there is no going back. Till date there is no permanent cure for this condition and one can only manage the disease through diet and lifestyle changes, slowing down the progression but not stopping it completely (Garg, 2022).

A look at the statistics and the financial implications of managing this illness reveal a morbid image. In India a large number of the population is too poor and can barely manage the bare minimum basic needs, any additional spending on health is out of their reach. On top of that the expenditure on dialysis which is costly as well as recurring is certainly not an option of survival for such people. The government health spending, which is a little over 1 per cent of gross domestic product, is among the lowest in the world. A report by the National Survey Office (NSO) based on 2017-18 studies revealed that overall very few Indians, only 14.1 per cent in rural areas and 19.1 per cent in urban areas had any form of private or government health insurance. Therefore for a vast majority of kidney patients the disease is unmanageable as dialysis and renal transplants are costly and require recurring expenditures (Garg, 2022).

As for my own self, it was a big struggle, first to come to terms with the issue that I was now one of them who needed regular dialysis for survival and then to think about the sources from where I could fund my dialysis expenditure. Luckily my insurance cover provided me some respite as it covered a part of the expenditures.

Methodology

Hospital premises are places where easy access is only available to either the patient or the attendant or caregiver. A researcher has no role here to invade the set-up of a hospital. But in this context, ironically I consider myself

lucky as being a dialysis patient myself, I was able to perform participant observation interacting freely with patients⁷, caregivers⁸ and the palliative care staff⁹. This paper is a personal narrative where I have explored my own life experiences, emotions and observations with respect to the dialysis unit using autoethnographic method.

The Patient and the Caregiver

'Relations of care produce outcomes that the logics of choice and cure miss' (McKearney & Amrith, 2021). When we as humans focus on relations of care, we build sustaining ties between us as social beings (Taylor, 2010). The feeling of care must have an empathetic engagement together with warm and sentimental rationality. Families are still the primary sites through which caring obligations are distributed (Goody, 1971). My autoethnographic journey through the dialysis unit has made me realise that love and care, nurtured by families, are the most potent elixirs of healing, infusing every step of the journey with hope, strength, and the unwavering belief that, together, we can conquer the most formidable of challenges. It has left me with a profound appreciation for the healers, patients, and families who navigate this labyrinth every day.

As I continued to move towards my bed looking at other patients on the beds I crossed, greeting some, stopping for a few minutes to talk to some patients and their caregivers, occasionally joking with the nursing staff and sometimes even commenting wittingly on one of them, Lalit, a male nurse, held out a box of sweets with a sweet smile. He had bought a new car. I smiled back and congratulated him wondering about the uniqueness of this place for it carried different meanings for different people. While for a patient and his caregiver, this place was a battleground of emotions, for medical practitioners, nurses (like Lalit), technicians and other hospital staff, it was their work place to earn their living and meet the necessities and luxuries of life.

Every step I was taking towards my bed, pretending to be brave and comfortable, my heart was racing rapidly. Moving through the dialysis unit it seemed like a journey through a world where machines were humming in synchrony with the rhythm of life, where every patient was a warrior in his/her daily battle against kidney disease. As I moved further crossing by the open cabins of other patients, the familiar scent of sanitisers and the reassuring chatter of staff and patients enveloped me with some relief. It was a place where the walls had heard countless life stories and where hope and resilience flourished amid adversity. The dialysis unit was not just a medical facility; it had become a second home for me and many others like me.

A known, innocent yet loud voice interrupted my thoughts calling out towards me “Aunty, where’s my chocolate?” As I looked towards the source of the voice, it was Mishu, a seven year old girl, the youngest patient of this unit. Big expressive eyes with thick black eyelashes, dusky skin and the sweetest smile, she talked less with her mouth but more with her facial expressions, expressing anger, fear and so many other emotions, all difficult to decipher. Her mother was willing to donate her child with one of her kidneys but Mishu was too frail and young to be able to sustain the transplant surgery. So she had to wait and take a better diet with well managed electrolyte balance. Till it was time for transplant, she had to undergo dialysis to be able to live. I took some quick steps towards her, searched in my purse and held out a chocolate and a pack of gems towards her, saying, “See I remembered my promise, now you must fulfil yours. So which poem are you going to recite for us today?” She quickly snatched the chocolates and hid behind her mother shyly peeping and smiling from there. Her mother smiled at me and said that Mishu was really giving everyone a tough time as she was not letting any nurse or technician touch her and insert the needles for dialysis. I remembered that some of the more sensitive patients had requested to not give them the bed near this kid as when the dialysis needles were inserted she shrieked and yelled in pain, which made them too nervous. It was only a few of the brave heart technicians who would tell her stories or play something interesting on the television screen to distract her and quickly prick her with those painful monsters. Keeping her stable for the next four hours of the procedure was another Herculean task for her mother.

The nurses and technicians who staff the dialysis unit are more than medical professionals; they are lifelines. Their compassion, knowledge, and unwavering support transform clinical encounters into profound human connections. As they navigate the complexities of each dialysis session, they also provide emotional support, turning strangers into friends.

Seeing Mishu always reminded me of my initial days here. My journey into the world of dialysis began with trepidation and uncertainty. I still remember the day I had my first dialysis. It was a path I hadn’t expected to traverse at this stage of my life, but chronic kidney disease had other plans for me. As I sat in the sterile, dimly lit waiting room of the dialysis center, I couldn’t help but reflect on the countless hours I had spent Googling what to expect. None of it had prepared me for the overwhelming mix of emotions and sensations that would engulf me during my first dialysis session. The waiting room felt like a purgatory of sorts, suspended between health and illness. The harsh fluorescent

lights cast an unforgiving pallor on the faces of the patients around me. Some looked weary and resigned, while others chatted quietly, offering comforting nods to the newcomers. The air was heavy with the palpable anxiety that clung to each of us. The anticipation had reached its zenith as the nurse called out my name. I followed her into the treatment area, where the intimidating bed appeared before me. Its white metallic frame seemed more like a throne of discomfort than salvation. I gingerly extended my arm, bracing myself for the cold touch of the needle. The moment it penetrated my skin, a sharp pain coursed through my arm, a stark reminder of my vulnerability. As I lay on my bed, I noticed the bank of machines that surrounded me, their rhythmic whirs and beeps filling the room. Each one was a lifeline, sustaining my fragile existence. The nurse explained the process, but her words seemed to vanish into an indistinguishable drone. I was too absorbed in the dance of numbers on the screens, tracking the vital metrics of my body, which had now become an alien territory. Amid the monotony and discomfort, I found solace in the unspoken camaraderie of my fellow patients. We exchanged knowing glances, shared smiles of encouragement, and occasionally engaged in whispered conversations about our lives beyond the dialysis center. In their eyes, I saw strength and resilience, a reminder that we were all in this battle together.

Coming back to the present (physically as well as mentally), I passed by the bed of Geeta Devi, an old woman in her early 70s, originally from Bihar, but now settled in Greater Noida with her son. She was always arguing and scolding the technicians to set the dialysis machine to extract more water from her blood so that she could get to drink just a little more water. The technicians would never agree as extracting water after a certain limit can be fatal for patients and Geeta Devi had already suffered a cardiac arrest few months back when she was given CPR¹⁰ and revived. One of the major problems faced by patients on haemodialysis is that their urine output gradually decreases and even becomes nil for those who have been on maintenance dialysis for long periods of time. During dialysis, blood is filtered through an artificial dialyser and all excess water is extracted from blood itself. So in between two consecutive dialysis, whatever water one drinks remains in the unfiltered blood and can be removed only on the next dialysis. Such patients are advised limited amount of fluid intake as fluid buildup in the body can cause breathlessness, cardiac arrest and death too.

This is also my story, one of the most profound challenges I face is the relentless thirst, an unquenchable desire for something as simple and essential as water. Dialysis, the very process that is supposed to help my failing kidneys,

is also the source of my unending thirst. It is a cruel irony that the treatment that sustains my life is also the one that denies me the simple pleasure of a sip of water. Life on dialysis seems like I am confined in a desert, with family members at home and nurses here, patrolling to ensure compliance, a restriction on my most basic human need. As the treatments became a regular part of my life, I couldn't bear the thirst any longer. Desperate pleadings for a few sips of water with those around seemed like a cruel curse, and those also would go unheard of quite often. "It's for your own safety," they'd say, and they were right, but it didn't make the thirst any easier to endure. Despite the rules and warnings, there were moments of rebellion. I'd stealthily take a guilty sip, feeling the cool, refreshing liquid soothe my parched throat. It was a fleeting moment of relief, but it carried the weight of disobedience. Occasionally, I now put an ice cube in my mouth on the guidance from my doctors and nutritionists, searching for ways to alleviate the thirst without compromising my health and avoiding complications.

My fight for drinking water is not just about physical thirst; it is a fight for dignity and control over my life. It is a reminder that even in the face of adversity and the strictest of rules, the human spirit persists in its quest for something as fundamental as water. Through this battle, I learned resilience and the importance of advocating for my own needs, even when faced with the most formidable challenges. My thirst for life, both metaphorical and literal, continues to drive me forward on this journey with chronic kidney disease.

On the very next bed, was a professor, Prof. M.N. Das who had started coming for dialysis from past one month. He had undergone a fistula¹¹ surgery in his hand but since the fistula was not healed or matured (as they call it in the medical terms) so he had to be dialysed using a point on his neck where a temporary intra-jugular catheter¹² was put for some days. He was exceptionally quiet since the day he had started coming to the hospital and neither smiled nor acknowledged greetings from anyone. His aged wife, his caregiver was always standing next to him, feeding him every hour during the entire dialysis duration as directed by the doctors so that his blood pressure and sugar levels were maintained. She was really alert and quick to respond to every beep and alarm of the dialysis machine immediately calling for the technicians or doctors to intervene and check if all was well. As for Prof. Das, it seemed that the shock of learning about renal disease was too much for him and he had already lost the will or desire to live. It was only his caregiver who was desperate to make him continue his journey. Sometimes, life does not go as per our plans, none of

us ever plan to fail in life but we fail to plan when unforeseen changes disrupt our smooth life.

As I reached my bed, neatly made with crisp white bed sheets and fresh pillow cover, a well sanitised dialysis machine, fitted with a new dialyser, with specific internal settings to suit my physiology as per the electrolyte balance in my body, stood next to the bed. The heart of the dialysis unit is the cadence, the rhythmic symphony of these machines, each one resembling a life support system. The hum of haemodialysis machines and the beeping of monitors provide a constant backdrop to our lives here. Each dialysis session is a lifeline, a crucial ritual that maintains patients' well-being while also tethering them to the limitations of their condition.

The moment I lied down, technician, Lijin and nurse, Missy came towards me with blood pressure cuffs, needles, and a sanitised tray with other required stuff. They greeted me and made one or two sharp comments about me gaining weight, saying that I was probably drinking more water than the permissible amount. The staff here had become almost like my extended family and they took care of me throughout the dialysis period of four hours, monitoring my parameters. A unique camaraderie forms among dialysis patients, and also among patients and the medical staff. They share their fears, hopes, and even their favourite dialysis-related jokes. The conversations in this space are unfiltered, driven by the understanding that only those who've walked in these shoes can truly comprehend the journey. In these moments, the dialysis unit becomes a sanctuary for shared experiences.

In the dialysis unit, time assumes a peculiar significance. Patients count not only hours but also sessions, and their lives become entwined with the regularity of their treatments. Hemodialysis becomes both a lifeline and a tether, binding patients to the unit while offering them the promise of longevity. Time takes on a different dimension during dialysis. To me it seemed that time here stretched and contorted, making each minute feel like an eternity. I watched as the machine methodically filtered my blood, and I couldn't help but ponder the fragility of life. In those moments, I realised how much I had taken for granted—health, time, and the freedom to live without being tethered to a machine.

Another patient that I really identified with was Niharika Sharma, her bed being on the far end of the room. Looking at her reminded me of myself and my family. She was in her late 20s and was diagnosed with kidney failure during the course of her first pregnancy. Just a year after giving birth to a girl child she had to be on dialysis. Her husband was always in the hospital with her small

infant daughter, as there was nobody else to take care of the child when both the parents were in the hospital. He could never let her be there alone for dialysis and so carried the kid tied to a baby pram kept in the waiting room, a little away from the dialysis ward as entry of children (except who were patients) was prohibited in this area. I really marvel at the love and care he had for his new family of hardly three years, as that is the time they had been married for, running to and fro between his wife and child. The appreciation for him comes from the fact that in spite of his struggles here in the hospital and also working in a private company, putting up with the additional financial burden, he was always smiling, also willing to run small errands for other patients.

These are just a few of the patients in the dialysis unit whose struggles and situations I identify with. There are many many more with myriad stories of pain, burden and grief behind them, yet most of them choose to move forward in life either on their own, or due to the love and care of those who support them and care for them.

We, patients in the dialysis unit carry the weight of our diagnosis with remarkable resilience. I've witnessed individuals from all walks of life tethered to their dialysis beds, reading, talking, or simply gazing into the distance. Even I spend my time watching my favourite movie or an interesting K-drama series on Netflix holding my mobile phone in one hand. But of course this continues only till my blood pressure or sugar levels have not dropped as then I drift into a very uncomfortable situation. Our stories reveal a tapestry of strength and courage in the face of chronic illness. Life on dialysis is about adaptation, and we patients are its masters.

My dialysis experience is a profound encounter with my own vulnerability. It marks the beginning of a journey I hadn't chosen, but one that I will continue to navigate with determination and hope. As I left the center that day, I couldn't help but reflect on the resilience of the human spirit and the profound bonds that form in the most unexpected places. Dialysis had become a part of my life, but it will not define it.

Conclusion

I sincerely feel that we as humans in social set-ups are always entangled in relationships of dependence, support, and sustenance and care. However, different societies build these caring relationships differently as to create significant differences at the level of who has the responsibility to provide care, which is seen to need and to deserve it, and what care aspires to do and be (McKearney & Megha, 2021). Apart from this the meanings people attach to

illness have real consequences in terms of whether they are motivated to seek treatment and how they cope with their symptoms. Also how supportive the patients' family and community is, is also a primary factor in determining how well they fare in the treatment. Family factors can protect against, or contribute to a patient's overall wellbeing despite of having a critical disease. Supportive families and good relationships can motivate a patient to continue to live happily.

However, the stark truth is that initially when a family member is diagnosed with any life threatening disease, all other members of the family are willing to stand up to the illness, all of them truly come out as care givers. But as time progresses, even the most sincere caregiver may wear out. Also the financial burden is the biggest reason for such scenarios. Only those who have an insurance, or pension or any other source of earning to support them, and also when the care-giver is relatively free from other burdens like working for a living, etc. can he/she sustain the dialysis schedule for a long period of time.

Life in a dialysis unit is a testament to the indomitable human spirit. It's a world where machines and medicine intersect with humanity and hope. My autoethnographic journey through this unit is just an attempt to illuminate the resilience of its inhabitants and the essential role played by healthcare professionals and caregivers. In this space, patients become soldiers, and each dialysis session is a chapter in their ongoing story of perseverance and courage.

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Notes

1. Nephrology is the branch of medicine that deals with the physiology and diseases of the kidneys.
2. Hemodialysis is a treatment to filter wastes and water from your blood, as your kidneys did when they were healthy. Hemodialysis helps control blood pressure and balance important minerals, such as potassium, sodium, and calcium, in your blood.
3. A kidney transplant is a surgery done to replace a diseased kidney with a healthy kidney from a donor. The kidney may come from a deceased organ donor or from a living donor.
4. Peritoneal dialysis is a treatment for kidney failure that uses the lining of your abdomen, or belly, to filter your blood inside your body.

5. End-Stage Renal Disease (ESRD) is a medical condition in which a person's kidneys cease functioning on a permanent basis leading to the need for a regular course of long-term dialysis or a kidney transplant to maintain life.
6. The glomerular filtration rate (GFR) shows how well the kidneys are filtering.
7. a person who is receiving medical treatment.
8. A person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy.
9. In general, the interdisciplinary palliative care team includes a doctor, a nurse, and a social worker. But other experts often fill out the team, according to a patient's needs.
10. CPR involves manual chest compressions and, in some cases, rescue ("mouth-to-mouth") breathing. If available, a device called an automated external defibrillator (AED) may be used to restart the heart. These interventions can keep blood flowing to the brain until emergency medical assistance arrives.
11. A fistula is a special connection that is made by joining a vein onto an artery, usually in your arm. This creates a large robust blood vessel that can be needled regularly for use during haemodialysis.
12. Intrajugular catheter for dialysis is a preferred route for hemodialysis catheters, for its ease in identification, big size and unhindered straight passage to the right atrium.

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