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“Blessing and Burden”: Negotiating the Hemodialysis Experience

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ABSTRACT

This exploratory study aims to examine the hemodialysis experience for patients with a focus on exploring perceptions of burden and dependence as well as kinship relations and social support systems. Through semi-structured ethnographic interviews with patients, the author describes how people define and assess the “burden” of dialysis, how they cope with the reality of being dependent on dialysis for an indefinite amount of time, the challenges they face daily, the social support systems available to them, and how kinship roles and relationships change because of dialysis. Understanding and empathizing with dialysis patients is key to designing effective and sensitive interventions to help ease the challenges and burden of treatment on patients and caregivers.

BACKGROUND

When a patient is diagnosed with end-stage renal disease (ESRD), most are put on hemodialysis, a treatment that filters the blood as a functioning kidney would. Patients with ESRD are treated with a form of dialysis, which is seen as a temporary solution with the ultimate goal being kidney transplantation for those that are determined to be viable candidates. Patients are bound to their dialysis machines for 3 to 4 hours, 2 to 3 times a week, which usually disrupts their normal life and activities, including work¹. Many are not able to support themselves financially or physically as the treatment takes a heavy toll on the body. Patients are likely to develop anemia, generalized infections, neurological damage, gastrointestinal bleeding, chronic headache, and bone disease with persistent treatment. In addition, regulatory hormones produced by the organ are not supplied by the machine.⁴

Previous studies have suggested that the stress of being dependent on the machine and treatment schedule can lead to depression among some patients. A study from 2001 found that five percent of dialysis patients commit suicide, and seven percent commit what is known as “passive suicide” by purposefully straying from their diets or dropping out of treatment programs.⁴ The indefinite nature of dialysis and the uncertainty of whether one will receive a kidney transplant can also contribute to stress and depression.

¹ Munson, Ronald. Raising the Dead Organ Transplants, Ethics, and Society. (New York: Oxford University Press, 2001), 113-114.

Other studies have shown that depression and stress not only affect dialysis patients, but also caregivers of dialysis patients.² In a 2011 cross-sectional study published in the journal *Nephrology Dialysis Transplantation*, 236 participants reported having unpaid caregivers and over 50% felt these caregivers were overextended.⁶ This study also showed that increased self-perceived burden of care was positively associated with worse depression and quality of life.³

² Arechabala, M. C., M. I. Catoni, E. Palma, and S. Barrios. 2011. "Depression and Self-Perceived Burden of Care by Hemodialysis Patients and their Caregivers." *Revista Panamericana De Salud Publica = Pan American Journal of Public Health* 30 (1): 74-79.

³ Rita S. Suri, Brett Larive, Amit X. Garg, Yoshio N. Hall, Andreas Pierratos, Glenn M. Chertow, Irina Gorodetskeya, Alan S. Kliger, and for the FHN Study Group. "Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials." *Nephrology Dialysis. Transplantation*. (2011) 26: 2316-2322. doi: 10.1093/ndt/gfr007

INTRODUCTION

“I always say I hate the site of blood, especially mine. It took me a long time to even just to get used to this, the idea, what they were doing to me. Pretty amazing.”

Patricia⁴ has a soft voice, so soft that the recording program on my laptop barely picks it up with the beeping of the dialysis machine, the conversations between technicians, and my shuffling of papers. I’m seated on one of those round, pleather stools without a back across from her in a beige, pleather armchair. Though I’ve never been to this particular outpatient dialysis center before⁵, the lingering scent in the air is familiar – a mix of vinegar for disinfecting, gauze and plastic surgical tape, and recycled air.

I had spent time at a dialysis facility off and on in 2011 when my mother was receiving treatment. She would drive to the center on her own, three times a week, in the early afternoon. On some days I would pick her up on my way home from school, and this is where I met Patricia. She had the same treatment time slot as my mom and sat in the chair next to her. While it became routine for me – to sit in a chair by her as the clock on the dialysis machine counted down the last few minutes like a timer, to apply pressure to her fistula to stop the bleeding, to gather her things while she stepped on the scale and reported her weight back to the technician – it wasn’t until after my mom received a transplant in January of 2012 that I realized how big of an issue dialysis was for her, for me, and for our family.

If you were new to the field of kidney disease and dialysis, you might start with a simple Google search. The National Kidney Foundation (NKF) is a reputable source for

⁴ All names have been changed for privacy purposes

⁵ Located in a suburb of Rochester, NY

kidney health information and provides some basics on what dialysis is like on its webpage.⁶ One frequently-asked-questions type of subpage caught my attention:

“Do dialysis patients feel normal?”

Many patients live normal lives except for the time needed for treatments. Dialysis usually makes you feel better because it helps many of the problems caused by kidney failure. You and your family will need time to get used to dialysis.

From my own personal experience and from my current research, I believe the answers provided, like this one are oversimplified and deceptive. In this paper, I want to convey what life is *really* like for hemodialysis patients – how people cope with the reality of being dependent on dialysis for an indefinite amount of time, the challenges they face daily, the social support systems available (or not available) to them, and how kinship roles and relationships change because of dialysis. I began looking at the topic of burden of care and soon realized that I was imposing my own definition of “burden” and sought a broader approach to the challenges patients face allowing my informants to teach me what and how dialysis affects daily lives.

Purpose

Prior studies have argued that caregiver burden has a tangible effect on the health of the patient, but they leave the concept of “caregiver burden” unexamined. Prior studies have also indicated that high levels of stress may lead to suicide and depression in a small percentage of patients. However, these studies have not explored the ways that the majority of patients adjust and adapt to this new lifestyle. How do patients cope with these changes in their lifestyles and the intimate relationships with caregivers that help them manage the treatment and its side effects?

⁶ <http://www.kidney.org/atoz/content/dialysisinfo.cfm>

The purpose of this research study is to study the qualitative experience of patients undergoing hemodialysis treatments for end stage renal disease. How do they experience and cope with the stress of treatment, and what constitutes “burden of care” from the point of view of the caregiver and patient? How does the idea of “burden” differ depending on the kinship relations between the patient and caregiver, and how do kinship relations change (if at all) while a patient is undergoing treatment?

Methodology

Between May and November 2013, I conducted four ethnographic interviews with patients⁷. I tried to make these interviews as dialogic as possible by sharing my own experiences with a family member on dialysis. To ensure confidentiality, I gained verbal consent and de-identified individuals in this final report. In addition, I conducted library research to explore the current literature on this topic and used personal family experience to inform my interview questions and interactions with my informants.

Four patients in the greater Rochester, NY area participated voluntarily and were not financially compensated. There were no enrollment restrictions based on gender, age, or racial and ethnic origin. Any adults who are currently receiving or who have received hemodialysis as a treatment for end stage renal disease in the past and their self-defined, unpaid caregivers (family, friends, etc.) were eligible for the study.

The primary research method was ethnographic interviews. The snowball method of getting in contact with subjects was used starting with personal contacts. These contacts recruited future subjects from their acquaintances. In addition, I approached potential subjects directly and handed out information letters at events hosted by the non-

⁷ All names have been changed for privacy purposes.

profit organization, Kidney Cares of Western New York. Interviews were conducted in person (at a time and location decided by the subject) and audiotaped.

I am entering into this research as an undergraduate that has never experienced any chronic medical conditions firsthand, let alone been on dialysis. I am influenced by my family's own experiences with dialysis as disclosed above. While I tried to stray away from using pre-defined terms like "burden of care," the preliminary research studies I had read prior to starting this project focused heavily on these terms and quantitatively measuring them. I hope to contribute some qualitative analysis to the current discourse to express the human side of dialysis and those affected by it with emphasis on the influence of empathy and understanding on future interventions and patient services. This is merely a preliminary study limited by the constraints of time, access to patients, and access to transportation among others. Further research can and should be done; possible topics include how kinship and caregiving roles change in the family setting and patient perception of illness.⁸

⁸ A note on methodology:

The majority of outpatient dialysis clinics in Rochester, NY are serviced by Fresenius Medical Care, an international dialysis service provider, even those under a community hospital or university. Though study recruitment did not take place at a Fresenius clinic, I was advised by the clinic director to pursue a corporate Fresenius Research agreement. This process was long and tedious as the contract was geared toward clinical research and pharmaceutical trials and required signatures ranging from the local clinic director up to the Fresenius Vice President of Clinical Research. The corporate study coordinator did not seem to understand the qualitative and exploratory nature of this HIPPA-exempt study and did not modify the contract to exclude the non-applicable clauses. After two months of negotiation, I decided not to pursue the contract. Upon hearing the news, the coordinator I had been working with offered to waive the one hundred dollar application fee. If not for the money, I am curious as to why Fresenius was so insistent on the contract – which included such clauses, as "Investigator will provide FMCNA [Fresenius] with the manuscript two (2) months prior to submission." After all, my study was not an evaluation or assessment of dialysis service or providers.

ETHNOGRAPHIC NARRATIVE

Patricia Williams, 73

“Well. I think for me it’s a blessing. Where would I be if I wasn’t here?”

This is how Patricia responded when I asked her to describe dialysis. Not a blessing in disguise, not a blessing at times, just a blessing.

Patricia has been on dialysis since March of 2010 when her kidneys failed due to complications with diabetes. The first time she experienced the treatment, she didn’t know much about the process or anyone on it, just the pamphlet her nephrologist provided and a couple of visits with a friend so she could choose a center. Nothing, certainly not a tour of a dialysis center, can prepare you for what it is like, and without knowing what to expect, dialysis can be a scary process. “Nobody ever did give me the whole case scenario. It’s okay, I’m not someone that needs to be practicing medicine, that’s why they get paid the big bucks...”

Now, at 73 years old, she has come to terms with this treatment – its limitations and its benefits. On a typical dialysis day, that is every Tuesday, Thursday, and Saturday, you’ll find her starting treatment in the basement of a rehabilitation center in a Rochester suburb at around 1:30 pm. Her weight, blood pressure, and temperature are taken before starting.

After a surgical procedure to create a graft or a fistula, usually in the upper arm, the machine connects to the body via two needles, one for the blood coming out and the second for the “cleaned” blood to re-enter the body. It’s not a painless process as the NKF website suggests:

You may have some discomfort when the needles are put into your fistula or graft, but most patients have no other problems. The dialysis treatment itself is painless...⁹.

At first Patricia tells me, she doesn't feel "anything" during dialysis, but I soon find out it wasn't always that way and she has gotten used to the "sticks," the process of inserting the needles into the graft. Since the graft is deeper, not just under the skin, it can be difficult for the technician to insert the needle into the graft on the first try; the graft can shift, the needle must be at the right angle, and most importantly, every person's graft is different. There are numbing creams and sprays available to dull the pain of needle insertion, but Patricia tells me that is not an option for her:

No, I don't use any of that. Well the cream, I used but then you have to wrap your arm in Saran wrap¹⁰ and that's kind of hard to do by yourself... And the spray stuff...that's expensive. It's not covered by your insurance. But after awhile, when they get it right, it doesn't hurt at all. Poking around sometimes that gets a little...I just close my eyes and sit there. Once they get to know you, you're okay. Sometimes it's sore. Sometimes...(beep of dialysis machine) ...my arm is black and blue and times they don't get it exactly right (beep) ...I've been lucky I don't have to go for a fistulogram which isn't pleasant.

Her treatment usually lasts around three hours during which Patricia enjoys watching the cooking channel, a self-proclaimed addiction. After treatment and the two needles are removed, gauze, surgical tape, and a clamp-like plastic clip that applies pressure are placed on her arm to stop the bleeding. After 15 to 30 minutes, the clips are removed and more tape is applied to ensure no blood escapes. After that, Patricia steps on the scale once again and wheels her walker to the elevator which takes her to the first floor lobby where she waits for her medical transport bus home.

⁹ <http://www.kidney.org/atoz/content/dialysisinfo.cfm>

¹⁰Plastic wrap is used to keep the cream in place as it could numb other parts of the arm. It must be applied about an hour before dialysis. For Patricia living alone, it was a difficult task to apply the cream and wrap her upper arm with only one hand.

Lifestyle Changes

We've been talking for over half an hour now, and I begin to wonder if she's getting tired as the technician came to check Patricia's temperature with an oral thermometer. I paused mid-question and told her to take her time assuming she would want a break, but to my surprise she spoke through a semi-closed mouth, "this doesn't stop me!" It's nice to know Patricia retains a sense of humor. That persevering attitude is very much valued in our contemporary society as is independence. However, Patricia has had to surrender some of her independence, like her car.

...driving even to turn your head and look out the back window, it wasn't easy. I wanted to end on a happy note, I didn't want to end up hurting anyone or myself, and I didn't want my kids to take away my keys! I wanted to make that decision on my own, and I think they're happy with it.

I see a lot of people, older than I am, that are in much better shape. Sometimes I get upset but that's the way it is. And people 88 years old doing wonderful things, you know? I think my health has a lot to do with. It changes your lifestyle. I gave up driving, can't come and go like I'd like to. You give all of that stuff up. And that's hard.

She now relies on Lift Line, a service provided by the city of Rochester for those with a disability that prevents use of Regional Transport Authority's fixed-route buses; eligibility is determined through the Americans with Disabilities Act application process. To get home after a tiring treatment, she has to wait a couple of hours for her ride: "But, it's okay. I read a good book. It's pleasant sitting up there, and I just wait it out."

The list of lifestyle changes grows longer.¹¹ In addition to ageing ("Growing old is not the golden years!"), Patricia faces high blood pressure, diabetes, arthritis, and

¹¹ It should be noted that a significant lifestyle change is diet, with particular emphasis on limiting potassium, phosphorus, and fluid intake. I chose not to focus on diet because Patricia did not emphasize it in our interactions.

cataracts requiring multiple ocular surgeries which have helped but have still left her with less than 20/20 vision. She reflects, “this is as good as it’s going to get.” While certain conditions, like diabetes, preceded her kidney failure, there is no doubt that they are affected by and in turn affect her dialysis treatments. Her energy level, especially, has been altered; dialysis is known to be an exhausting process.

Just like kind of a long day. I’m older now, and I don’t have as much energy as I used to, of course...My lifestyle is very simple, very quiet. It’s not a lot to take care of...Dialysis is rough and tires me. And you notice the difference on the odd days¹²... You have to watch...your diet and it’s just life (beep).

Despite the side effects, Patricia is grateful: “I’d never thought I’d be happy about coming to dialysis. They’re nice people.” Her current clinic is a small center with only 5 stations compared to her last center which had 30 stations, more than the Monroe County average of 18. Patricia explicitly expressed her satisfaction with her current center throughout our time together: “And they’re all busy over there [at the old center], there’s not time for the little extras that we have here, just the nice-ities...If you have to do something, I’d rather be happy about it.”

Patricia’s nephrologist said she would make an excellent candidate for a transplant. In the time I spent with Patricia, it was common for her to mention the status quo and a lack of control over it, the “normal” course of events indicated by the repetition of phrases like “it’s just life” or “that’s the way life is” and most noticeably, her decision to turn down the opportunity for a transplant.

I’m sure there’s someone younger than I am that could use it more... there are younger much younger people who have kids and families that you know would probably be more receptive. When it’s my time, it’s my time in this stage of the game.

¹² Odd days refers to non-dialysis days.

She seemed to justify her limitations by stating, multiple times, that she was not a medical professional and therefore did not need to know the details of her condition and treatment.

I'm not trying to be a practicing physician so I don't ask any questions! I always tell the dentist when he tries to put me on the TV and show me what he's doing. If I wanted to be a dentist, I would have done it. Wake me when it's over.

This aligns with her view that other patients in her position are also uninformed:

[Another patient's] daughter is very aggressive; she wanted to know what was going on and who was dealing with her dad and all that. She's just on top of everything. How much he understands, I don't know... I don't think anybody is informed but if you ask, they will try to help you. But how do you know what to ask?

It also seems like understanding it from a medical perspective and coming to terms with it physically and emotionally are two different things:

I couldn't look at the machine for months. I didn't know anything from it. I just bury my head in the ground, go ahead and do what you want to do. Wake me when it's over.

I realize now that coping with the reality of being on dialysis isn't a one-time action; it's constant negotiation and re-negotiation, and there are multiple perspectives. Coming to terms with and understanding the physiological process did not follow the same timelines as coming to terms with and understanding the emotional side effects.

Support Systems:

Apart from her cats, Patricia has been living alone since her husband passed away in 2010. She recently had surgery on her foot, and her 22-year-old grandson, Paul is staying with her and is helping her take care of herself.

He's my caregiver now after my surgery...I say he should go into the medical field. He does as nice a job of wrapping my feet as the nurses do. I mean he's not squeamish...He cleans it, socks it.

Paul is the oldest of Patricia's 8 grandchildren, 4 of whom are local. While day to day she is on her own, Patricia counts on her children to help her with chores. After church on Sundays, she goes grocery shopping with her daughter. "If I need anything in between, the big heavy stuff, my son lives [in a nearby suburb] so he'll pick up medications or a big bag of cat food."

When it comes to medical care, Patricia considers both friends as well as family to be caregivers. While she seems genuinely touched that they're present: "They've been so insistent on asking, that they care enough to do that," I sense some hesitation when she takes about her children's level of involvement in her care.

It's nice if everybody was informed. We have a little bit of a jump on that because my daughter-in-law is a nurse practitioner in orthopedics, but they know a lot, and she can help [my son] understand it. My daughter she doesn't want to know anything about it. She has no bedside manner. I hope it doesn't come back to bite her. The idea of all of it; they're all very understanding, they don't give me a hard time about it if I decide I don't want to do something or go somewhere because I'm tired...They have to be really understanding of people's feelings. I don't think you want to be babied, but it is nice for people to understand that you know, you don't always feel like jumping in with both feet...

There seems to be a delicate balance among her caregivers between involvement (but not infantilizing), understanding (Patricia's physical and emotional limits), and empathy (without having experienced dialysis themselves). She prefers her son to accompany her to doctor's appointments because of his wife's medical background, as mentioned above, but sometimes a friend takes Patricia: "My other friend who goes to the doctors with me, she just, she actually sounds happy if you ask her to do that..." Patricia makes a special effort to make these trips enjoyable and convenient for people by

booking multiple appointments in a day and treating her son or friend to lunch or a “fun” stop in between.

A friend who loves the garden store, I miss not being able to jump in the car and take a trip to the nursery, so we do those things [doctors appointments and outings] together, hopefully a little fun for her too... They're always asking. In fact, she said let's just plan for once a month.

When you do those things, it gives you time to spend with friends who might not have that time... you get to your doctor's appointment and you have time to chew the fat, women always love to talk! It's turned out to be a good experience. That's what it is.

Many of Patricia's friends are also part of her church community, which as a whole is another great support system for her. She has been a member of Rochester's Pinnacle Lutheran Church for the last 50 years. The congregation there is aware of her kidney failure and was helpful in taking turns coordinating rides and meals in her first 3 months of dialysis.

Self-Burden:

Beneath the cheery disposition, there are days that take extra effort for Patricia to get going: “Some days it's not always easy, some days I hardly want to get out of the [dialysis] chair and do anything, but I push myself.” I sense there is a certain responsibility, or burden, on Patricia. For example, she must make these trips, chores, and tasks enjoyable for her caregiver. They are “good experiences” as long as she *makes* them so:

[re: errands and trips to the doctor] The only person that's going to make it unpleasant is me...

It's interesting, a lot of my friends try to compensate, try to understand what I was going through, but a lot of it has to do with the patient – you're making it something that's hard, that's difficult...

Asking for help is a topic that Patricia brought up on her own.

I'm not one to unnecessarily impose on other people, but you do have to learn to ask which would happen if I was on dialysis or not. There's always a doctor's appointment or something going on and I could take the Lift Line. I like to take my son with me to the doctor's because I like him to hear, you know an extra set of ears. I do impose on him to do that. The hairdresser my daughter takes me to most of the time, but I do have a friend that I could call. There are 2 or 3 really good friends that [inaudible]. I've gotten better about [asking for help].

Another instance is when Patricia talked about her interactions with family. She finds it hard to "keep up" with her children's lives in the way that she used to because she lacks the energy. Enjoying the company of her family used to be pleasant, but now there is self-perception of burden, of "an old lady to take care of":

P: My energy level is huge. I used to go everywhere and spend my time with kids, and now a lot of that I don't go to because I think they don't need an old lady to take care of as well. Kids are older now, they have their own lives. That's the toughest thing for me to come back to, they keep going on without me but that's the normal course of events, I guess. I'm thankful for the time I've had, I enjoy whatever time that they do spend with me. Some of those things you just can't change. And I think if you don't accept them then you're in worse shape.

A: Yeah...because then you're fighting it?

P: That's right. Constantly...pushing against it. I can't keep up with their lifestyle. I do see the kids so that's a plus, when they've completely wiped me off the chalkboard – sometimes I think they'd like to...

What struck me was the way she interprets this situation. It is almost a double bind of agency. When her agency is limited ("Some of those things you just can't change"), she has no choice but to accept them or end up "in worse shape." The alternative, the ultimate decision per se, is to not push back, to accept reality including its limitations.

A significant cutback in Patricia's life is family vacation time. Her family vacations in Canada, and Patricia used to go with them and drive an hour each way to a

dialysis center in Watertown, New York, an arrangement made by her social worker.

With decreased mobility, it has become harder to make those one hour commutes three times a week. She has recently stopped going all together to make it easier on her family, to lessen the burden of catering to her dialysis needs even when on vacation. She now no longer accompanies the family to Canada:

I needed a friend to go with me, and I didn't want to take my kids away from their vacation. To take a whole day out of their time. I took a friend with me and she drove down to Watertown because dialysis isn't covered in Canada. It was an hour drive to Watertown and then back. It wasn't a very pleasant experience.

Not wanting to take away from the family vacation or not wanting to worry her children in general is a theme that reoccurred in Patricia's narrative. She is extremely aware of her presence within the family, and what she brings along with a suitcase. Her attitude towards this hard decision to not attend family vacations anymore can be summed up in one simple sentence: "Better to just acclimate yourself than to just fight it."

Phil Arnold, 70 and his wife, Cathy

I was humbled to be invited to Phil and Cathy's home in a close suburb. After one year of treatment, he received a kidney from his sister in 2000 that lasted eleven years until a bout of pneumonia caused it to clot and put him back on hemodialysis. The hardest part of starting treatment over a decade ago was the anticipation of not knowing what to expect. His nephrologist talked about it, and he attended a demonstrative workshop on peritoneal dialysis at the local hospital (which proved the at-home style of treatment was not right for him), but nothing really prepared him for what he was to encounter. Looking back, Cathy says nothing could have prepared them, not just for the treatment but its side effects and wishes they had been able to visit a center, to meet the providers, get a feel for the experience. It would be helpful to have an orientation and some interaction with current dialysis patients. Nonetheless, Phil says "I don't see it as a negative experience."

Lifestyle Changes

While Phil used to balance full-time work and treatment, driving himself and maintaining hobbies, dialysis and comorbid conditions (including diabetes, congestive heart failure, arthritis in the knees and carpal tunnel in the hands) limit his mobility and have changed that lifestyle. His treatment time now is inconsistent; Cathy drives him as early as 6:30 some mornings. It makes it difficult for these retired schoolteachers to schedule looking after their eight grandchildren after school. His plans for retirement were "interrupted". What was supposed to be the stage in life for spending time with family, part-time work in a golf shop, playing golf with friends, and trips to the Adirondacks is interrupted by frequent exhaustion – Phil describes his post dialysis as a

unique kind of weakness and fatigue after which he needs time to recover: “Basically three days a week, he’s out,” Cathy comments.

Similarly to Patricia’s circumstances, travel isn’t impossible, but it does require extra planning. The Arnold’s have a yearly family trip to Myrtle Beach during spring break for which the social worker has helped Phil schedule treatments in that city. They also spend Labor Day weekend in the Adirondacks. For this trip, Phil gets treatment on two consecutive days to last him the weekend. It’s inconvenient and tiring, but Phil seems rather nonchalant: “We’re learning to be a little more flexible.”

Support Systems

When Phil first started treatment, his three children were all under the age of thirteen. They were stoic, they didn’t want to talk about their father’s illness, and group counseling “fell flat.” Perhaps that influenced the family’s decision not to inform their grandchildren about Phil’s condition. Their parents haven’t discussed it with them, and Phil and Cathy are fine with it being that way. “They think [Phil] is fragile,” Cathy admits. Cathy is more likely to sense when he needs help: “He doesn’t have to ask for help.” Occasionally friends pick him up from treatment and their neighbors mow the lawn. He’s always been active and is, understandably, a bit stubborn to accept help, but Phil says “pain makes dependence acceptable.”

There used to be more visitors during his treatment time when Phil first started. Now, it’s mostly fellow patients that Phil socializes with if he’s not chatting with techs or watching TV during treatment. Both Cathy and Phil reflect on the relationship patients have with each other. When Phil was on a regular schedule, he would see the same patients and get to know them. Then one day, one might not show up. And the next

treatment, still no sign. Vacation, transplantation, death? There's no way of knowing which. Privacy regulations prevent techs from reporting on a patient's condition – for better or for worse. Phil recalls a time he asked point blank, if the patient who used to sit in the chair next to him had passed away. “They're very straightforward about death, ‘so and so is dead.’” I can feel the mood in the Arnold's living room change. Fortunately for Phil, his wife was always by his side. Married for forty-six years, together for fifty-three. “You went through it with me” he says to her, and I feel privileged to be in the room with them at this moment.

It was also important that he developed a good rapport with the clinicians at the center. Since his transplanted kidney failed, there has been no correspondence with the transplant clinicians who used to be in contact every six months for check ups and monitoring and the NKF chapter¹³, what he calls “the kidney people”. Now the dialysis technicians, social workers, nurses and other clinicians are the people with whom he is most in touch. Phil has some reservations about Fresenius for creating very long, sometimes fourteen-hour shifts at low pay, causing good workers to leave. They are clearly understaffed. The techs and nurses Phil does see regularly, seem to be reliable and comforting people – “they're nice people, caring...we're a family.”

Caregiver support systems: When I ask Cathy what resources were at her disposal, as a caregiver not a patient, Phil jumps in instead – a reoccurring event that made me reconsider my decision to interview the couple simultaneously; maybe I would have heard more from Cathy if we were alone. “She's gone to every doctor's

¹³ The Rochester NKF chapter closed in 2011 due to a lack of revenue. A new 501(c)3 non-profit, Kidney Cares has formed to fill the needs left behind, but is still in its beginning phases of development.

appointment, taking notes. I have a tendency to forget things... When I was in [the hospital] for nine weeks, she was there every day and had a diary of everything that went on.” Cathy acknowledges she gets some support from family, but having a friend with a significant other with a lot of health problems with whom she can relate has been a major help. This friend told her “This is why we’re so healthy – our deal on this earth is to take care of our spouses.”

Transplantation

Age as well as Phil’s heart condition are two reasons why Phil is not on the active transplant waiting list. A few family members, neighbors, and friends were potential donors but all were either non-matches or were unqualified for other reasons such as smoking or high blood pressure. That leaves the option of a cadaver donor which Phil averages would take about five years, putting him in his mid-70s. His heart isn’t that strong and even though Phil’s cardiologist technically cleared him for transplantation, both patient and doctor acknowledge the risks of undergoing surgery given the circumstances.

What was more interesting than these two reasons, to me at least, was the Arnold’s attitude towards transplantation, an experience they had already undergone just a decade earlier. Having a transplant wasn’t ideal, “it wasn’t a picnic” in Cathy’s own words. When I ask her to expand, Phil offers his own response. Immunosuppressant medications – up to forty-three pills per day at first – made Phil extremely vulnerable to infection and made him insulin-dependent whereas now his diabetes is managed through pills which, including phosphorus-binders and blood thinners, total ten per day. Given the couple’s transplant experience, I was curious about their expectations before

transplantation. Did they know transplantation would be so stressful? Not so, based on what they had heard from someone who had received a kidney and was a “new person” because of it. “We both were very torn [between dialysis and transplant],” Cathy says. The scheduling and time commitment comes up again, as does constant swelling in Phil’s legs and the hassle of frequently changing medications and doses. What’s new is Cathy’s addition that every time Phil got sick, it was a “life and death feeling” because the kidney was so fragile, so precious. Trips to the emergency room always incited fear of what was wrong with the kidney and would the kidney be okay. “It was very stressful...” she says, “Sure it was nice having the freedom from dialysis, but...I don’t know.” Later on, Phil echoes these sentiments of freedom: “It does free you up. We had talked about traveling around the country, going to Europe, not that we can’t now, but it would be difficult.” ///

Samuel Blaise, 41

“B-24,” the Kidney Cares volunteer announces. I’m playing Bingo at the organization’s annual community picnic in Ontario Beach Park. There’s a small crowd, only about 20 people give or take. “Any luck?” I ask the gentleman next to me at the picnic table. After a friendly conversation, I’m introduced to his wife, both seem to be in their 60s or so, and their son, Sam who looks around 30. Mr. Blaise does most of the talking, and I’m surprised to learn it is Sam, not his parents, who is currently on dialysis. When we meet up two weeks later for an interview, I’m unsure of how the interview will turn out as Sam arrived solo even though I made sure to invite the family. I am grateful that he was extremely open and comfortable with the subject despite a furrowed brow that made me wonder if my questions were too personal. He insisted they weren’t and told me more than I had even thought to ask, only pausing to stutter or to gather his thoughts.

Sam works full-time in the purchasing department of a local non-profit service center. “Luckily I have a flexible job. Sometimes I don’t feel that great, and they let me work later [on another day].” Three out of the five days of the working week, after work, Sam drives himself to his second shift: dialysis. The evening shift tends to house younger patients to accommodate work or other commitments. In a very matter-of-fact tone, Sam says he gets hooked up quickly, is on for three hours, takes fifteen minutes to disconnect and wait for his fistula to clot, and grabs something to eat on the way home, a short commute. Normally, he doesn’t feel that bad after treatment. About once a month, he gets worn out. “It’s like you’ve partied too much” he says. “Without the party?” I joke. “Exactly!”

There are three groups of medical professionals, Sam tells me, particularly among the nurses rather than the nurse practitioners or doctors. The first group is good at what they do and cares about the patients. The second group is good at what they do, but it's just a job to them. And the third group is not very good and doesn't really care about the patients. "In all of my fifteen years of dialysis, you meet all three groups of people...If you don't like the people...the three hours can be a lot longer." His interactions with social workers are minimal, "only when I need to sign something."

Support Systems

Sam lives alone, his parents thirty to forty minutes away in the outskirts of the greater Rochester area, but he feels very independent. When I asked who he would call, if he did need help, he said his parents are an option, but "most of the time, I just wait until I feel better." Emotionally he seems pretty self-sufficient as well. Sam's main concern regarding his family is that they worry. They don't have to drive Sam to treatments or anything, but they do check up on him over the phone. "It's more from an emotional standpoint than a physical one."

He attended the kidney support group when the Rochester NKF chapter existed in Rochester and would consider attending another group if they started up under the newly-formed replacement, Kidney Cares. The group he used to attend was run by a lady whose husband had been on dialysis and later received a transplant. Everyone's story was different – some had transplants, some were on peritoneal dialysis, etc. Each session lasted about two hours, most times there was no agenda. Unless there was a guest speaker, like a social worker, any topic was fair game for discussion. When the group was dissolved, there were only a few people left in it.

Sam was in the unique position of being a caregiver to his sister who also experienced kidney issues starting in 1993. Even after her transplant, complications with her native kidneys caused seizures and she was in the hospital frequently. Sam and his sister overlapped at one point, they were on dialysis during the same time period.

S: We did more things together because of it, but we didn't talk about it. It was almost an unwritten thing. We didn't want to show each other...if... we were having the same problems, but we uh did more things together. Like she worked as a cashier and customer service rep in [department store] and I would pick her up during her lunch break and we would like go to the movies together. I think um...if we did [talk about it] it was more in a general sense, not as much how we were feeling.

A: Do you think your relationship would have been different with her had you not been going through the same circumstances?

S: I mean I guess we were close as brother and sister but I think I – I – I it brought us closer, since we did.

Sam's sister passed away in 2004, at the age of 23. The autopsy revealed that her medication dosages were off. Every time doctors tried to lower her dosages, she would start to reject the organ and thus had to be kept on very high dosages which took a heavy toll on her body. One of the side effects that went under the radar was clogged arteries leading to a heart attack.

The more we talk, the more I learned about Sam's family. His mother had undergone six months of chemotherapy for ovarian cancer just prior to his sister's diagnosis. I asked Sam to compare chemotherapy and dialysis, in terms of its demand on families:

I guess it's in a way they're alike. That you know um you know...either being on hemodialysis or chemotherapy, I'm sure you feel worse on chemotherapy but um you know there's some similarities. I guess in one way it's it's one way harder because usually during chemotherapy you're feeling a lot worse...there's worry about dying. With dialysis as long as you don't have other issues, you know you can um, usually you don't have to worry as much about dying. Chemotherapy you

can get off of it sooner. Hopefully and then you'll be okay. Dialysis is more of uh well transplant but it's it's [A: more long term?] yeah, long term. It doesn't seem as serious but um, anyway.

Transplantation

Sam was diagnosed with kidney failure due to a rare disease called Focal Segmental Glomerulosclerosis in 1994 and had four years to “prepare” for the transition to dialysis which he started in 1998. Perhaps because he was young (in his 20s at the time) or perhaps in some twist of fate, he received a kidney that same year only for it to fail less than two weeks later, before he even had the chance to leave the hospital. First, a vein broke putting him back into surgery followed by an infection that led to him having to get the kidney removed, another surgery. He worries that going back to the OR for another transplant would lead him down the same path as his sister. Another complication arises when Sam goes into surgery, his potassium spikes, a risk worth consideration after the surgeries he's already had. Lastly, he confides a third hesitation is the pressure and responsibility, perhaps burden, that would result for his parents.

S: I hate to – especially for my parents – go get the transplant and then something goes bad...If I knew, I was married and had family members or something...they're [Sam's parents] are much older than I, I hate to have them, because they've already been through it many times [with Sam's sister], I would hate to have them go through. Because with the transplant, there's ups and downs and also you know for at least the first few months, I would lose my independence. You can't drive for a while and you've got all these appointments so yeah, there's a part of me that really wants to do it...

Sam has been on the transplant waiting list since November of 1997 since, technically, his first operation was unsuccessful. There's only one caveat: he requested to only get a call if they find a perfect match, a situation that Sam admits “that's virtually never going to happen.” He can call and request to be on the active list and take any kidney that is a reasonable match if he wanted to, but he is waiting until he can't take dialysis anymore.

He's seen first hand what they went through with his sister, says "I worry now because now they're older" recalling an incident two years ago in which his father fell and broke his collarbone. Sam does not want them "to go through that all over again" now that there's higher chances they would get sick. "Besides them worrying about me, is not you know if I get a transplant...for them, all the way in [town, thirty to forty minutes away]. If I knew more people, I might be more inclined to do that. At least at first, I wouldn't be as independent with the transplant."

Roseanne Carter, 40s

Roseanne is a self-proclaimed patient advocate. With a nursing degree and a wealth of dialysis experience under her belt, she's a real veteran to the field. She graciously accepted my invitation to meet at a local library for an interview. Her story starts differently than the others – with a rare genetic condition called medullary cystic kidney disease causing her kidneys to fail at the age of eight. Hemodialysis then was a “primitive process” without the more compact machines available today. Plus immunosuppressant medications were not as developed so she was put on very high doses of the steroid prednisone, a very damaging drug when used long term. She received a transplant from a cadaver donor at age ten (“kids don't thrive on dialysis”) which lasted eighteen years. She received her second transplant in 1995, which lasted another six years.

Now back on dialysis, Roseanne spends her treatment time managing her E-bay business, playing phone games, or people watching. She's afraid to fall asleep for fear of another near-death experience – the last time she dozed off and didn't keep a careful eye out, the dialyzer wasn't tightened enough and a liter of blood was on the floor when she awoke. She had to be rushed to the hospital for a blood transfusion. Roseanne is a bit cautious at first: “I'm not putting them [the dialysis clinicians] down, but things happen.” I reassure her and she elaborates on her other concerns. She's allergic to the standard fluid used to clean the lines¹⁴ - like any allergic reaction, it causes itchiness but it's even more painful because it's her blood that's itchy. She requires a special bio-allergenic

¹⁴ the pipes through which blood flows out of the body, through the machine, and back into the body

dialyzer fluid, the lines must be rinsed with two bags of saline instead of the normal one, and she requires Benadryl to counter any potential reactions.

“I feel I live a pretty normal, active life despite dialysis.” Like the other patients I have talked to, Roseanne acknowledges the exhaustion that often follows treatment and said she and her boyfriend “don’t plan much” on dialysis days because how she feels after is unpredictable, it is a draining two and a half hours. “Anxiety is my biggest problem,” she says. Her past experiences (as described above) aren’t much reassurance for the future. She is on the fence about a third transplant and is not currently on the active waiting list.

I could possibly have a third transplant. But the more antibodies you build up toward you know reject another one plus if you have a blood transfusion that messes with your antibodies. Plus I’ve had two and you know suppression, I’ve already had so much prednisone so I’m worried about that...Most people say transplant is a cure-all, but it’s not. It’s trading one set of problems for another set of problems.

Support Systems

Roseanne lived alone for a while and currently lives with her boyfriend. When she had a transplant, she was working two jobs – “I’m not used to depending on people.” Now that she is not working full-time and also gave up her car which depressed her for months, she is learning to depend more on others. Loss of independence is a “downfall of the whole chronic illness.”

Roseanne said she didn’t date much. “It really takes a special person to deal with the chronic illness with you and if you’re not together for a long time, it doesn’t work!” she says with a chuckle. Her current boyfriend has a few illness to contend with: “I guess we take care of each other, and I like that.” Roseanne hesitates when I ask if she considers her boyfriend to be a caregiver. “When I was sick yes, but I’m not sick now.”

The relationship is a very positive thing for Roseanne – with a house, and a garden, and her boyfriend “life is infinitely better.” He understands her needs and treats her well – I hear about her birthday celebration that he arranged just last week.

I don't like being a burden on people...I told him [before we met] I was independent, working, and now I'm so – and he stopped me and said 'don't think, you're not so' – he doesn't think about me that way.

Aside from intimate relationships, Roseanne has made use of community services and programming offered by the NKF when it existed: “I was so upset when NKF left.” She played bowling and table tennis in the “Transplant Games” (a national Olympics of sorts for transplant recipients, donors, and their families), received financial help a few times, including a scholarship to get her pharmacy technician certification, and discovered her passion for patient advocacy – it was a branch of NKF of sorts. She hasn't been involved with Kidney Cares – “it's kind of fizzled out, the Kidney Foundation was very...active” and Roseanne knew the executive director and a few others from the foundation.

Patient Advocacy

Her allergies and past experiences strengthen her resolve to be her own advocate, even though she was once told by a clinician: “oh, if you're not nice or whatever, if you tell on me...I won't give you a Benadryl.” Given the circumstances, she still “people watches” during her treatment, and by that she's referring to the new clinicians to make sure they're abiding by the protocols. There's a high employee turnover at the clinic and Roseanne feels the need to look out for her and other patients' “own well-being.” Given serious oversights that have occurred in the past, it's no wonder Roseanne feels so much anxiety about treatment. “I just watch...and then I pick what I want to take care of.”

After her second transplant failed, and a brief exposure to peritoneal dialysis resulted in complications, Roseanne returned to hemodialysis: “To see the machine again and have all those needles, I was petrified.” There was really no one, besides a nurse practitioner that helped her transition. Social workers, she says, are overburdened with paperwork and it detracts from their ability to interact with patients on an emotional level: “It’s a financial job, now.” The programming that’s done now is often incongruent with patient needs. Roseanne recalls a raffle for patients for a turkey when half of the patients live in nursing homes and have no use for a turkey. Or the time they gave out a third-grade activity (coloring, puzzles, etc.) book to occupy their time. “One thing that’s lacking is a social worker / counselor to go around and ask how this affects you.” Roseanne feels that her age-group, middle-aged fairly healthy patients are left out because most patients are elderly and fragile. “We’re the ones who need counseling.”

Though dialysis has come a long way from the “primitive process” Roseanne experienced in the 1970s, she is quick to point out the limitations of technology. The machines, for example may spout some scientific reading, but that does not equate to how a patient feels. Roseanne has been questioned, “how can you possibly feel *this* when the machine reads *that*?” She doesn’t sound bitter when she tells the story, just reflective, even hopeful with suggestions on how to improve clinician understanding: “It takes a special kind of person...I think when people are hired for dialysis clinics, there should be a patient – maybe an orientation that says ‘this is what you need to know as an employee,’ but from a patient’s point of view.” Plus according to Roseanne, the new computer systems don’t have the capacity for individualization

Besides making mistakes, clinicians sometimes patronize patients. Roseanne likes to be, and is certainly capable, of being involved in her care. She makes an effort to research and learn about her treatment. For example, when a new machine the “crit-line,” a device that monitors absolute hematocrit and oxygen saturation in the blood was introduced, Roseanne did her own research online to understand it yet was told “you wouldn’t be able to understand everything we got educated on” by a nurse. “One of the big things is being treated like second-class citizens, like you’re beneath [them]...Don’t treat me like an invalid...probably ninety-percent of patients feel demeaned.”

Overall, Roseanne has some great ideas to improve the dialysis experience. Like Phil, Roseanne is troubled by the privacy restraints that prevent patients from knowing when their fellow patients pass away. Roseanne would like to see a memory board of sorts to commemorate the deceased instead of just watching them pass way without notice. “At dialysis, you see one little aspect of their entire life,” she says, reflecting on a patient who had passed away. Upon reading her obituary, Roseanne learned she was a retired professor, among other details. Another idea is to start a blog, maybe focusing on dialysis-friendly recipes to help patients manage their diet. And of course, that new employee orientation – from a patient point of view – to break down that wall between patients and employees.

They think patients will rise up, we just want what’s right for us...They go home regardless of what they do. If something goes wrong with my treatment, I have to deal with it for the rest of the day, potentially until the next treatment.

Stemming off of her role as a patient advocate under NKF, Roseanne has continued her advocacy. The previous social workers facilitated by connecting Roseanne with new patients that were looking for advice and someone to talk to. Advice ranges from ‘bring a

blanket, it gets cold' to more serious topics like making sure someone knows your medical history in case you are found unconscious. Lately, the referrals have slowed down. "I just want to help people get through this; it's not fun. It's something you cope with, but it's not fun....If I can make it, you know, easier...If I can do anything that will help."

DISCUSSION

Looking back, I am surprised at the wealth of knowledge I have learned by simply listening, and I am extremely grateful for the way my informants opened up to me and received my curiosity with such kindness. A few themes present themselves: perceptions of kidney transplantation, the comparison of dialysis to a "second shift" or job, a negotiation of normalcy, and the need for patient services.

In most cases, dialysis is a temporary treatment, the ultimate goal being kidney transplantation from a living or cadaver donor. Transplantation comes with its own set of complications like infections from the surgery itself, organ rejection, and a lifetime of being immune suppressed, among others. Nonetheless, transplantation is considered the best renal replacement therapy – patients are shown to live longer and from an economic point of view, it is less costly than persistent dialysis¹⁵. Despite these benefits, and of no surprise to my informants, transplantation is not a panacea for kidney disease or even lifestyle complications due to dialysis.

¹⁵ Hu, R.-H., et al. "Medical Cost Difference Between Renal Transplantation and Hemodialysis." *Transplantation Proceedings* 30.7 (Nov. 1998): 3617-3620. Web.

My initial thought that life on dialysis is without a doubt a more burdensome lifestyle than kidney transplantation was not correct. My informants, particularly those who have had unsuccessful transplants in the past find dialysis to be a lifestyle that is less burdensome because the risk of surgery as well as the post-surgery complications that arise from immunosuppression would be a bigger burden on their families and a less desirable lifestyle. Phil mentioned the upside of transplantation being mobility, less exhaustion, and a smaller time commitment, but it would come at the cost of managing his diabetes via pills rather than insulin (his first transplant made him insulin-dependent), fewer medications overall, and less fear of protecting such a fragile organ. Torn between the two, Phil calls this state being “in limbo.” Sam also worries that a transplant would result in a loss of independence during the quarter-year recovery process. Roseanne captured the dilemma well when she said: “Most people say transplant is a cure-all, but it’s not. It’s trading one set of problems for another set of problems.”

A second theme from the interviews was the comparison of dialysis to a second job. Most treatments are three times a week and last three to four hours during which the patient cannot get up from the dialysis chair. Missing a treatment is risky – the dialysis machine acts as an artificial kidney, filtering fluids that would otherwise accumulate in the body. Unfortunately it is a second job that doesn’t fall within the hours of 9 to 5. Even on non-treatment days, patients must watch their diets (limiting nutrient intake like potassium) and restrict fluids. Consuming more fluids requires a stronger treatment and may cause heart damage. Three of my four informants had experience working full-time while receiving dialysis and had to schedule shifts – the term used even in the clinical

setting – in the evenings like Sam or experiment with at-home peritoneal dialysis like Roseanne.

There also seems to be a hierarchy one could compare to a workplace. When I started my research, I approached the clinic's medical director. Questions about more-detailed patient needs resulted in a referral to a nurse practitioner who was thought to spend more time with patients than directors. This provided me with some insight, but again, ended with a recommendation to talk to a social worker whose purpose is to attend to social needs. While I received a wealth of information from the social worker, patients didn't seem eager to recommend them as knowledgeable. As Roseanne alluded to, social workers don't have the time to interact with patients because of responsibilities like sorting out insurance and transportation. Both Phil and Patricia worked with a social worker to arrange dialysis treatments while on vacation, but other than that, they had limited interactions. Furthermore, there is a "wall" between patients and clinicians in which the former are often expected to show up, be courteous, and be silent about concerns: "oh, if you're not nice or whatever, if you tell on me...I won't give you a Benadryl." It seems that patients' social needs are at the bottom of this hierarchy. Even lower on the totem pole? Patients themselves.

Normalcy complements the theme of burden. For Roseanne ("I feel I live a pretty normal, active life despite dialysis"), normalcy is something that she was able to maintain even with dialysis treatments. Being active and independent, physically and socially, was an important part of achieving normalcy. On the other hand, Patricia's sense of normalcy was compounded by changing family relationships, including the aging of her children into adults with their own lives and families, and her worry of posing a burden on them:

“That’s the toughest thing for me to come back to, [my children] keep going on without me but that’s the normal course of events, I guess.” Compounded further by other health issues and aging in general, it seems as though Patricia has come to accept a “new” normal, which inevitably includes personal sacrifices (ie: independence and mobility) as well as social sacrifices (ie: not vacationing with the family). In just these two narratives, there is a diversity of experiences. Yet, as mentioned earlier, NKF guidelines claim that normalcy is possible and should be expected for dialysis patients: “Many patients live normal lives except for the time needed for treatments.” Individual narratives show that normalcy is disrupted by more than just time needed for treatments including social relationships and constraints on agency, to name a couple. What does it mean for a national, institutional narrative to portray the dialysis experience as relatively undistruptive? Is there space in this dominant narrative for a diversity of individual experiences in achieving normalcy? A larger sample size would be needed to unpack these ideas.

Lastly, the data indicates a tremendous need for patient services on a more personal level. The centers seem understaffed given that each patient has unique needs. Social workers seem overwhelmed with the number of patients as well as with their responsibilities of coordinating insurance payments and logistics of getting to and from dialysis. There is little time left for patient interaction, for acknowledging and responding to more intangible patient needs and rights. Some of these are as simple as the right to know about their treatment and why certain decisions have been made and others are more complex such as managing changing relationships with family and feeling like a

burden (see: Patricia). A holistic approach to caring for patients is absolutely necessary because, in Roseanne's words, "At dialysis you see one little aspect of their entire life."

I began this study curious to unpack the term "burden" in the ever-popular phrase "burden of care" or "caregiver burden." I now realize that it is indefinable. Relying on a pre-defined notion of "burden" is limiting. Burden includes physical limitations like fatigue or infection and lifestyle changes but it surpasses these – whether they used the word "burden" or not, I found each informant alluded to some unavoidable imposition on family or friends – it is Phil's ideology that "pain makes dependence acceptable," it's Patricia's decision to opt out of the family vacation, it's Sam's awareness of his parents' worry and involvement if he pursued a transplant, it's Cathy finding comfort in a friend whose spouse also has a chronic illness, it's Roseanne telling me that her boyfriend was her caregiver "When I was sick, yes, *but I'm not sick now*" (emphasis added).

When I was talking with Patricia about how friends and family try to understand her situation, I told her, "I guess you can't always put yourself in someone's shoes" and she caught me by surprise when she said, "They're not always shoes that you would want yourself to be put in." While this may be true, it seems vital for dialysis patients to interact with someone who knows what it is like from experience. Even caregivers, regardless of compassionate intentions, may never grasp the reality their loved ones face. Patient advocacy, as Roseanne stressed, is key. Moving forward, as we expand our services and pursue more interactions, as we strive to ease "the burden" on dialysis patients and their caregivers, how can we help if we don't fully understand? Understanding is the key to empathy and developing compassionate care.

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