

# Fluid illness

## Dialysis, undercare, and the social life of kidney disease in rural Guatemala

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### Abstract

In response to the rising rate of end-stage renal disease (ESRD) in Guatemala, the public health system established a national community-based dialysis program to enable people living in rural areas to complete treatment in their homes. Here we explore how this newly available, life-prolonging technology has altered local worlds by transforming ESRD from an acute, life-ending illness into a managed chronic condition with an uncertain trajectory. Through case studies, we describe how living with dialysis influences family relations and caregiving in rural Guatemala. We find that dialysis interacts with an insufficient health care system, one that avoids life-ending complications but does not sufficiently manage life-altering symptoms. In addition, the need to care for people with ESRD for an uncertain amount of time may disrupt and strain family-based caregiving networks. Amid this meager health and social welfare infrastructure, life on dialysis exacerbates the chronic insecurity and structural inequality of life in postwar Guatemala. As both life and illness are prolonged through dialysis, the unceasing demands of the treatment and illness strain the webs of obligation and care that Guatemalan families and communities have developed to adapt to their decentralized and fragmented public health care system.

### Keywords

rural, dialysis, indigenous, caregiving, Guatemala

## Introduction

‘I feel I have an artificial life’, Alma remarked one afternoon, sitting at her kitchen table in a dim, cinderblock-walled room in a forested town in the Guatemalan highlands. We had been discussing peritoneal dialysis, a life-prolonging treatment for end-stage renal disease (ESRD). For the last two years, Alma had performed dialysis on herself four times a day, every day. Looming over us were towers of cardboard boxes filled with dialysis solution that, together with a few wooden planks, formed shelves on which Alma stored mugs and plates. She did dialysis every four hours: warming a bag of dialysate, scrubbing her hands twenty times in every direction, connecting the bag to her abdominal catheter, then sitting for thirty minutes while she exchanged the dialysate for the fluid in her abdomen, which would then sit and collect uremic toxins and water until her next exchange. The whole process left her feeling nauseous, cold, and tired. ‘I live by the clock’, she exclaimed, ‘I drop everything to do dialysis. . . . You have to leave your life to do it, and this time can never be recovered’.

Alma developed ESRD in her late thirties as a complication of longstanding, undertreated diabetes. As a single mother, given her strict and time-consuming dialysis regimen, she struggled to care for her daughter on her own. She could no longer earn her own income. Her younger sister often helped with cooking, cleaning, and childcare; and her brother living in the United States sent remittances to support her financially. Her father helped care for his granddaughter but rarely helped Alma care for herself, reasoning that getting out of bed to do dialysis would strengthen her. Alma wished she could once more jog through the cornfields surrounding her town, walk to the vegetable market, or simply eat without the dietary restrictions of her disease. She took solace in the presence of her daughter, although Alma no longer had the energy to play with her.

A year after this interview, Alma died. At age forty-one, she succumbed to complications of ESRD. Yet long before her death, life as she knew it had been transformed until it became nearly unrecognizable. As the incidence of kidney disease and dialysis use continues to rise around the world (Jagger and Fraser 2017), stories like this are becoming more common. Alma was but one of a growing number of people with ESRD living in lower-resource areas like rural Guatemala with limited access to dialysis. In ESRD, kidneys no longer adequately filter the blood, and eventually people require replacement therapy in the form of hemodialysis, peritoneal dialysis, or kidney transplantation. While transplantation is considered the first-line intervention, it is expensive and depends on organ availability, and is thus not an option for many people, including those living in Guatemala where the national transplantation rate is less than six percent (Cusumano, Rosa-Diez, and Gonzalez-Bedat 2016). Instead, many people with ESRD depend on lifelong dialysis to survive.

There are two kinds of dialysis. Hemodialysis is a mechanical filtering of the blood by pumping it through a dialyzer, then back into the body, typically in four-hour sessions, three times per week. These sessions occur in centralized dialysis facilities often located in urban centers. Globally, hemodialysis is more commonly used, especially in high-income areas where it is a profitable venture. Peritoneal dialysis, on the other hand, removes uremic toxins and water by exchanging abdominal fluid through a permanent catheter multiple times each day; these exchanges may be gravity driven, allowing people to undergo dialysis in their homes without machinery. Peritoneal dialysis offers similar survival rates and quality of life at lower cost, and is more common in low-resource areas. Still, particularly in low- and middle-income countries, each year millions of patients with ESRD do not receive renal replacement therapy and die prematurely (Liyanage et al. 2015; Anand, Bitton, and Gaziano 2013). To expand access to dialysis in low-resource settings, some have established community-based peritoneal dialysis programs, for instance in China (Jiang and Yu 2011), Colombia (Sanabria et al. 2015), Sri Lanka (Nanayakkara et al. 2017), and Guatemala (Flood et al. 2017). These programs enable people who are marginalized from health care systems to both initiate and continue dialysis.

In high-income countries, multiple studies have explored how dialysis affects the lives and identities of patients, families, and caregivers (Tijerina 2009; Lindsay, Macgregor, and Fry 2014; McQuoid 2017; Kierans and Maynooth 2001; Constantinou 2012), and the ethical implications of using dialysis to prolong the lives of people who are not candidates for kidney transplantation (Russ, Shim, and Kaufman 2005). In lower-income countries, dialysis research tends to focus on strategies to disseminate services to more patients, reduce rates of infection, and improve patient adherence. However, several ethnographers have written important accounts of ESRD and dialysis in lower-income countries that demonstrate how social inequality, state neglect, and health care disparities shape experiences of ESRD and dialysis (Moran-Thomas 2012; Burnette and Kickett 2009; Crowley-Matoka 2005; Hamdy 2008).

Here, we contribute to this literature by exploring how, given limited access to health care, the burden of caring for people with ESRD falls to kin and community. In particular, we draw on the notion of ‘undercare’ defined by Feldman (2017, 53) as partial care provided within ‘system[s] of concern’ that are fragmented, unreliable, and inadequate. The expansion of dialysis into rural Guatemala transforms a once-fatal condition into a chronic managed state, one that is dependent on undercare – minimal and precarious biomedical health care – around which entire households and caregiving webs reconfigure. In this article, we use case studies to explore the use of dialysis in rural Guatemala, interrogating how the lives of those on dialysis are nurtured and prolonged, and how dialysis and undercare interact with local caregiving networks.

The research presented here is part of a larger study of how people live with terminal illness in rural indigenous communities in the highlands of Western Guatemala. In particular, we draw on twenty-three home visits and interviews conducted by Jillian Moore with two men and two women with ESRD and their families, in June and July 2014, and again between September 2016 and May 2017. At the time of these visits, the participants were between thirty-seven and forty-seven years old. Jorge, Pedro, and Elena identify as indigenous Maya, and Alma as mixed ethnicity. Pedro, Elena, and Alma developed ESRD due to complications from undertreated diabetes, and Jorge developed ESRD of uncertain etiology. All four received medical consultation at the Unidad Nacional de Atención al Enfermo Renal Crónico (National Unit for Chronic Kidney Disease Care, or UNAERC), the public nephrology clinic in Guatemala City. Jorge received hemodialysis at the UNAERC unit, and the other three performed peritoneal dialysis in their homes.

All four were also patients of Wuqu' Kawoq – Maya Health Alliance (hereafter Wuqu' Kawoq), a nongovernmental organization providing health care to people living with chronic illnesses in rural communities. All authors of this paper are clinicians or researchers affiliated with Wuqu' Kawoq, and our affiliation with this civil society organization has afforded us opportunities to interact with patients and families in their homes. We also have professional relationships with UNAERC and the other public health care entities mentioned in this study. Our intention is not to provide a unilateral critique of the care provided by these institutions; instead, we offer this perspective of chronic illness in rural Guatemala as a supplement to public health narratives about life-prolonging technologies like dialysis, in the hope of raising questions about the collateral and often unrecognized consequences of dialysis for local caregiving networks.

## End-stage renal disease in rural Guatemala

Guatemala has one of the highest levels of poverty and income inequality in Latin America, which especially impacts rural and indigenous Maya communities (Cabrera, Lustig, and Morán 2015; Ministerio de Salud Pública y Asistencia Social (MSPAS), Instituto Nacional de Estadística (INE), and ICF International 2017). This inequality has complex political and economic roots in the concentration of agricultural land holdings, a weak tax code, free-trade agreements that have transformed rural economies and consumption patterns, and public-sector corruption and fraud. Importantly, rural Maya communities have also been subjected to organized violence and discrimination, most notably during the thirty-six-year civil war. However, since the end of the war in 1996, peace agreement provisions to alleviate inequality have been poorly implemented (Oglesby and Nelson 2016), and efforts to restructure primary health care have been largely ineffective, with continued over-investment in specialty and hospital-based health care. As a result, in Guatemala, hospital-level resources exist to

treat end-stage complications of chronic diseases, but for most communities, preventive and early treatments are largely unavailable (Chary and Rohloff 2015).

One chronic disease rapidly becoming more common in rural Guatemala is chronic kidney disease (CKD), most of which is attributable to a rising prevalence of undertreated diabetes (Rosa-Diez et al. 2014). While the epidemiologic shifts leading to higher rates of diabetes are often accounted for with theories of transitions towards sedentary lifestyles, these transitions themselves are in part driven by socioeconomic and political inequity (Nulu 2017), including the ways free-trade agreements and international food policies have influenced rural-to-urban migration patterns and the turn from traditional staple crops to nontraditional export crops (Gálvez 2018; Flood and Rohloff 2015; Chary et al. 2012).

Together with these epidemiologic transitions, poor access to primary and preventative health care hastens the progression of diseases like CKD (Garcia-Garcia et al. 2015). Although some public primary health care does exist in Guatemala and is free to all citizens, it is designed to address acute and episodic conditions, and is not resourced to care for people with chronic illnesses like diabetes or CKD (Maupin 2009). Public health posts are understaffed and lack basic equipment and medications for managing chronic diseases. For example, most facilities do not stock insulin, a medication commonly required to halt the progression of diabetes and prevent kidney failure. Given these deficiencies in public primary health care, most people seek biomedical care for their chronic illnesses in the private sector, funded out-of-pocket as their finances allow, and turn to kin and community for additional support (Chary et al. 2012). At Wuqu' Kawoq, most people we care for with diabetes or CKD seek our care after years without regular or reliable biomedical care. For some, the transition to ESRD and entry into a peritoneal dialysis program may be their first stable relationship with biomedicine.

Another factor contributing to rising rates of ESRD in Guatemala is a recently recognized epidemic of 'chronic kidney disease of nontraditional causes' (CKDnT) primarily in young agricultural laborers without common risk factors for CKD like hypertension or diabetes. Although the causes of CKDnT continue to be debated, the leading theory is that CKDnT results from kidney injury caused by recurrent dehydration and heat stress (Silva, Albert, and Jayasekara 2017; Laux et al. 2015; Correa-Rotter, Wesseling, and Johnson 2014). Similar epidemics exist in India, Egypt, and Sri Lanka where people also withstand strenuous agricultural labor in heat and high humidity. However, because strenuous agricultural labor is by no means a new phenomenon in Guatemala or elsewhere, the confluence of factors and vulnerabilities underlying the epidemic remains a topic of ongoing research.

Regardless of how people develop kidney disease, in Guatemala many cases of CKD progress to ESRD requiring dialysis. In fact, Guatemala has one of the highest per capita

rates of peritoneal dialysis in the world (Jain et al. 2012). Most rural Guatemalans do not have access to insurance-based care provided by social security and military facilities and instead seek dialysis through UNAERC, an institution founded after the civil war and tasked with caring for poor patients with kidney disease. The first nephrology department in Guatemala was founded within the social security health system, the Instituto Guatemalteco de Seguridad Social (Guatemalan Institute of Social Security, or IGSS). In 1992, IGSS created the first peritoneal dialysis program in the country with support from Baxter, a corporation that produces dialysis supplies. With time, IGSS nephrologists began to also care for patients without social security insurance, through a program overseen by the Order of Malta, a Catholic humanitarian organization that had received dialysate donations from private companies in the United States and was searching for a way to make use of them (Lou Meda 2011). Then in 1997, with funds from the Order of Malta, the Guatemalan government founded UNAERC to assume care for all peritoneal dialysis patients once cared for through the IGSS charity services.

By recent count, UNAERC now has a caseload of about 4,500 dialysis patients and each month accepts more than one hundred new patients requiring therapy (UNAERC, n.d.). UNAERC shoulders a daunting responsibility, as it lacks the capacity to care for its rapidly growing and extremely underserved patient population, and it functions within a larger primary health care system that does little to prevent or slow the progression of CKD (Muñoz Palala 2016). For people on peritoneal dialysis, UNAERC provides the resources necessary for dialysis itself, including dialysate, catheters, and laboratory monitoring of dialysis function, all through government-contracted private corporations. However, UNAERC does not have the resources to offer patients comprehensive care, including diagnostic exams or medications for conditions commonly associated with ESRD like anemia, mineral bone disease, diabetes, and hypertension. Therefore, while access to dialysis technology keeps people from swiftly dying of ESRD, these individuals receive minimal care for the symptoms and comorbidities that arise as the disease progresses. Furthermore, since kidney transplantation is largely unavailable in Guatemala, kidney dialysis is not a temporary bridge to curative treatment as is often the case in higher-income settings. The situation in Guatemala is similar to that described by Moran-Thomas (2012, 202–203) in Belize, where diabetic nephropathy is also common and access to dialysis is limited; in this context, dialysis becomes a ‘holding measure against death . . . stretching the remainders of time’.

The case studies we share demonstrate how in rural Guatemala, experiences of ESRD and dialysis are shaped by the patchy and unreliable system of undercare through which people gain access to a biomedical technology that prolongs their lives and illnesses. Lives structured around dialysis provided through undercare become defined more by the unknown than the known, more by the uncertain than the certain. Furthermore, in a place

where illnesses are understood and addressed communally (Chary 2015), this uncertainty reaches beyond the individual and encompasses entire families and communities in narratives of struggle and irresolution.

## Undercare

Jorge lives in a rural highland village with his wife and five sons. From childhood, he supported his family through subsistence farming and logging trees, until his early thirties when his kidneys failed. He had been healthy until one day he began to feel nauseous and noticed his feet and face were swollen. These symptoms worsened over the next week until he finally sought care at a public hospital where he was diagnosed with kidney failure and referred to UNAERC. For the next two years, Jorge performed peritoneal dialysis in his home. After developing multiple abdominal infections, he transitioned to hemodialysis in Guatemala City. Now, twice a week Jorge leaves home before sunrise on a four-hour journey by public bus to arrive at UNAERC by nine in the morning. If he is late, his appointment and machine are given to another patient. The hemodialysis lasts four hours, during which Jorge waits while his blood whirs through a machine. Afterwards, he makes the four-hour trip home.

These bus trips cost US\$40 per month, but for the last six years, because of his disease, Jorge has not had the stamina to farm or log trees, and thus has earned no income. Instead, his wife and mother earn money washing clothes or collecting firewood, in addition to tending to their home and the five boys. Their wages are used for food, electricity, and schooling, as well as the bus fares for Jorge. To supplement these earnings, Jorge seeks support from charitable organizations. Wuqu' Kawoq provides him primary care and medications for conditions associated with his kidney disease, and when our finances allow, we fund a portion of the bus fares. Another charitable organization donates school supplies and clothing for his sons. Sometimes the family borrows money from neighbors, unsure of how or when they will pay them back. When money is particularly tight, Jorge skips treatment, which leaves him feeling even more tired and nauseous than usual. Although his life has been extended by dialysis, for Jorge and his family, this prolonged life is a state of perpetual uncertainty.

Like Jorge and his family, many people in rural Guatemala live with unpredictable and unreliable sources of income, food, and health care. In the rural areas of Guatemala, most households are landless or land poor, with farming plots too small to maintain subsistence. To earn incomes, families rely on short-term, physically intensive jobs without contracts or benefits (Krznaric 2006). These labor conditions can, as they did for Jorge, provoke or accelerate the progression of chronic illnesses like CKD. When kidneys fail, biomedicine

offers patients dialysis, which staves off death but is not itself curative. In Guatemala, organ transplant is exceedingly rare due to the resource and financial constraints on institutions providing kidney care. Furthermore, medications to alleviate the symptoms caused by both dialysis and disease progression – fatigue, nausea, swelling, loss of appetite – are expensive and unsubsidized. Dialysis supports life, but only at the point of death: minimal care serving only to prolong vital bodily functions to keep people alive amid crisis, but not to help them thrive (Redfield 2012).

Without adequate ancillary support from the institutions providing dialysis, people ‘make do’ (de Certeau 1984) by mobilizing social networks – family, friends, churches, and increasingly, nongovernmental organizations like Wuqu’ Kawoq – to fill gaping holes in their care (Chary and Rohloff 2015). However, just like the people they seek to help, organizations like ours face unpredictable financial and existential futures, relying on transient funding from disparate sources to provide patchwork care for chronic illnesses like kidney disease that do not capture the imaginaries of global health donors and policy makers (Baird 2018). As clinicians and companions of the patients we serve, we also find ourselves improvising and ‘making do’.

Peter Rohloff, a physician who has cared for Jorge for several years, regularly confronts the reality that Jorge’s persistent weakness and fatigue are due to insufficient dialysis. Jorge receives dialysis twice weekly based on the availability of machines at the UNAERC facility, but ideally he would receive three or more sessions per week. After one clinic visit with Jorge, out of frustration Peter exclaimed to Jillian, ‘His neck veins are up to his ears, and he has high blood pressure. The only way to fix this is more dialysis. Everything else is like moving chairs on the Titanic’. Despite these constraints, we continue to do what we can to offset inadequacies in UNAERC care and manage his dialysis-related symptoms. For example, to treat his anemia Peter continues to prescribe erythropoietin, a very costly medication that Wuqu’ Kawoq can only afford to subsidize at half the optimal dose. Thus we watch his illness unfold, uncertain of how long our organization, Jorge and his family can each bear the tensions produced at the intersection of the necessities of disease and the inaccessibility of treatment.

In this way, life-prolonging technologies like dialysis push those in civil society to their caregiving limits. Approaching these limits is especially unsettling for us as physicians and reluctant humanitarians educated in an individualistic society infused with discourses of human rights and autonomy, from which we have absorbed the notion that everyone has a right to access the medical care required to keep them alive. In alignment with this idea, patients who would have otherwise had a swift and perhaps painless death now depend on a minimal technology within a substandard health care system. Caring for these individuals, it

is unsettling to ask ourselves whether it is possible that these technologies have in the end caused more harm than good, as we watch families struggle and strive to get by each day, and as we ourselves feel the palpable and disquieting uncertainty that infuses their lives and defines their futures.

Pedro, who lives with peritoneal dialysis and who we discuss below, describes the anxiety engendered by this existential uncertainty: ‘the hope is that through this medicine [dialysis] one can live, but for how long? . . . [The doctors] do not know what will happen, and neither do we: what will happen in the course of time while on dialysis’. For dialysis patients, caregivers, and family members, this uncertainty is emblematic of undercare (Feldman 2017). In Guatemala, undercare keeps individuals with severe chronic illness alive, but not in ways that foster dignified and whole lives. Rather, they work constantly to compensate for the scarcity and fragility that surrounds them, using ground-level ‘tactics’ (de Certeau 1984) to resist precarity: taking advantage of opportunities as they come and to mobilizing existing social networks and their resources. In this way, an advanced biomedical technology like dialysis may preserve life while simultaneously reinforcing the violent and unequal social and political structures that create the conditions for disease in the first place (Kalofonos 2010; Feldman 2017; Stevenson 2012). Through dialysis, Jorge has lived years beyond his diagnosis, yet he has spent those years feeling exhausted and weak, and unable to live as he wishes. Furthermore, his wife and mother labor each day to earn bus fares, replace his lost income, and procure basic necessities for their family. Keeping up with the incessant demands of dialysis can push people to their limits, perhaps threatening to exceed their capacity to ‘make do’.

## Life-limiting technologies

Jorge’s hemodialysis trips are only possible due to the exceptional efforts of his family and financial support from community-based organizations. Many other people cannot access these serendipitous resources (Baird 2018), and as a result may discontinue or never initiate treatment. In recent years, community-based peritoneal dialysis programs have emerged as an important public health response to this need (Nanayakkara et al. 2017; Liyanage et al. 2015). Advocates of these programs, like the UNAERC peritoneal dialysis program in Guatemala, insist that all people deserve life-prolonging treatment, no matter their circumstances. The UNAERC website promotes its peritoneal dialysis program in terms of autonomy and enablement:

Most people enjoy the independence and flexibility they get with peritoneal dialysis. . . . It provides the freedom to dialyze and manage the disease mainly from your home. . . . The material you need to do it arrives at the door of your house, and you only have to go to the clinic every six weeks. . . . People on peritoneal dialysis treatment can lead normal lives. . . . You can maintain the balance of your normal work with minimal interruption by therapy.

In the remainder of this article, we explore these assertions by examining the experiences of three people who use peritoneal dialysis. We show that although peritoneal dialysis does alleviate some of the financial and logistical stressors that people like Jorge experience while on hemodialysis, with peritoneal dialysis undercare continues to affect families and communities through the symptoms caused by dialysis and disease, both of which create needs for intensive caregiving.

‘I am like a little baby’, Pedro observed, as his wife Luz transferred him from their bed onto his wheelchair and tucked his atrophied legs under a wool blanket. Pedro once supported his family as a carpenter, until eight years ago when he was diagnosed with diabetes. Because the local public health clinics were inaccessible and unreliable, and he could not afford private health care, Pedro lived for years without treatment. He gradually became emaciated, blind, and unable to walk. One day a local midwife introduced Pedro to Wuqu’ Kawoq, and he began treatment with us. However, irreversible damage had already been done, and several months later he developed ESRD. Our organization referred him to UNAERC, and he began peritoneal dialysis in his home. Pedro has performed peritoneal dialysis four times daily for nearly three years. Due to nerve damage from diabetes, he cannot live independently, and Luz and their four children must help him walk, bathe, toilet, and do the dialysis treatments.

Through peritoneal dialysis, Pedro has continued to live when he would otherwise have died. The treatments relieve distressing symptoms like nausea and swelling, allowing him to engage in some activities that bring him joy: being with his children, singing, praying with friends from his church. However, while peritoneal dialysis enables Pedro to live at home surrounded by his community, the treatment has significant effects on his wife and children, who work to adapt and keep up with the demands of dialysis and ESRD. As Jain (1999, 40) writes, prosthetic technologies have effects ‘that are enabling in certain capacities for certain people and disabling for overlapping sets of bodies and interests’. In this case, Pedro relies entirely on his wife Luz for care and dialysis. She earns their household income weaving traditional Maya belts between dialysis sessions and her other chores and errands. She finishes two belts each month, for which she earns the US\$30 they use for food, transportation, and education expenses. Luz once earned more as a housekeeper, but she

had to abandon this job because she would have to interrupt her workday to return home to help Pedro with dialysis. She explained, 'If you go to work, they want you to be there working. You cannot show up, and then go home in one or two hours. . . . But I have to give him my time. Any free time, I give to him for his medication [dialysis]. This must be done because this treatment is his life . . . only through dialysis does he have life'. Luz structures her life knowing her husband will depend upon her continued presence and effort for the foreseeable and uncertain future.

People with chronic illnesses often depend on affective labor: the labor of caregiving and social reproduction most commonly performed by women like Luz. The efficacy of home peritoneal dialysis often depends on the affective labor of kin and community, gendered labor which remains implied and unspoken. So too in biomedicine, a medical system in which practitioners often focus on how interventions affect individual bodies imagined as bounded and autonomous rather than within the webs of care and obligation, on which they and the efficacy of many biomedical treatments depend. As physicians it is easy to narrow our vision to a single circumscribed body in an attempt to simplify illnesses that are socially complex, diffusing across bodily borders. But biomedical care that neglects the social context of disease and that 'conceives of life as artificially severed from community' may fail to address how care offered without understanding this context may in fact be harmful (Stevenson 2012, 605).

Indeed, in many settings individual bodies and lives cannot be so easily cleaved from the bodies and lives of their kin and community. Especially amid material scarcity and with indeterminate disease trajectories, caregiving may significantly constrain the agency and life chances of these primary caregivers (Bergstrom and Heymann 2005). As Luz describes:

I have to take him to [UNAERC], and that requires money, as do the medications. . . . And [Pedro] requires care: moving him into the sun, taking him out for a walk, and other things. I have to take him to check-ups with [the nurse]. My time is a factor for me: money makes this so . . . for while someone is supported economically, she can achieve things. But if someone does not have [economic support], it is as if she were tied down. She cannot move forwards or backwards along the four cardinal points.

As a caregiver for someone with debilitating illness, Luz must adhere to demanding treatment regimens, but she is also a mother and the primary provider for her household. She simultaneously feels pulled in multiple directions and paralyzed, unable to fulfill any of the obligations she confronts on a daily basis.

Home dialysis even imposes significant limits on people less debilitated and still able to care for themselves. For example, Alma was a young woman living with ESRD who performed

her own home dialysis treatments. Until the day she died, Alma was the primary caregiver for her young daughter, though her ability to care for her was limited by weakness, fatigue, and the demands of dialysis treatments, rendering it difficult to leave the home. She had to quit work because she could not find an employer who would allow her a private space for dialysis, or the time to return home for treatment. Instead, she lived on money from her father and remittances from her brother. Elena, another single mother performing home dialysis on her own, described how dialysis was the defining feature of her life: ‘I basically live to do my treatment’. Throughout their illnesses, Alma and Elena continued to support themselves and their dependents. In Guatemala, women living with chronic illness are often not exempt from their caregiving obligations as men are, given gendered norms devaluing the labor and lives of women, and gendered expectations of care that have been well established and documented elsewhere (Chary 2015; Moore et al. 2017; Webb 2015; Ehlers 2000)

In these ways, home dialysis defines, governs, and limits the very lives it prolongs. Compared with hemodialysis, peritoneal dialysis allows people to access treatment in their homes, making treatment more feasible and accessible. But this does not mean that people who use peritoneal dialysis have no need for institutional support, support currently provided by kin and community who themselves struggle with competing priorities. Furthermore, home dialysis regimens are time-consuming and restrict physical mobility. Each of these limitations are directly at odds with the tactics commonly employed by individuals in rural Guatemala in response to financial or acute medical emergencies, like seeking jobs in the informal labor market, exchanging favors in social networks, or offering short-term, intensive care (Chary and Rohloff 2015). Affective and productive labor are not commonly considered fundamental to the efficacy of peritoneal dialysis programs, even though many patients require sustained intensive care from others to use the technology and engage in activities of daily living. These caregiving demands affect the abilities of those involved – most often women – to tend to other obligations and earn their livelihoods. While home peritoneal dialysis may enable one individual to live, someone must nurture this prolonged life, whether that is the patient or her kin and community. When dialysis is reimagined to be both life enabling and life limiting, these essential labors begin to materialize.

## Chronicity and care

Elena lives in the same highland town where Alma once lived. She also uses home peritoneal dialysis. When Alma was alive they often traveled together to UNAERC appointments and became close friends. Elena once remarked that ESRD was more difficult for Alma than for herself. She explained, ‘[Alma] has a daughter, so she has to fight. But my work is done’, referring to her three adult children. Indeed, Alma cared for her daughter Nina despite her

symptoms and the demands of dialysis. But sometimes Alma would feel too tired to rise from bed to do her treatment, let alone walk Nina to school. With so many absences, Nina had to repeat the third grade. Alma's sister Lupe recalled: 'near the end of her life it was not [Alma] who cared for [Nina], but [Nina] who cared for [Alma]. She would find her lying on the ground with low [blood] sugar, and even though [Alma] weighed more than her, [Nina] would have to take care of her mother'.

On the day Alma died, it was Nina who found her mother collapsed on the bathroom floor. Now Lupe – who also has diabetes and CKD – cares for Nina in addition to her own two children, just as she promised Alma she would. Livingston (2010, 6; emphasis in the original) describes illness as 'something that happens between people', an idea we have encountered repeatedly while caring for people living with dialysis in Guatemala. Families adapt to the caregiving needs of illness and the rigorous demands imposed on them by dialysis. Yet these gendered webs of obligation and care can fray when illness is protracted over many years and as new responsibilities evolve.

Having escaped an abusive marriage, Elena raised three children on her own with wages from her small eatery. She worked hard to provide for her children. 'In my imagination, when my children grew up, they would support me'. This has not been the case. Elena observed how her care for others has gone unreciprocated: 'when my mother was dying [of diabetes], I was with her every day, by her side. If she wanted porridge, I made her porridge. I made anything she wanted . . . but nobody does these things for me. I have no one but God'. Indeed, Elena largely cares for herself. She lives off her own savings from the sale of a parcel of land. She prepares her own food, administers her insulin injections, and does dialysis on her own, despite poor eyesight and fingers numbed by peripheral neuropathy. When Elena has low blood sugar, she often lies in her bed and waits, because there is no one to bring her a glass of juice.

Yet Elena does not live alone. For years, she has lived with her daughter Lucy and her son-in-law. When she first became ill, Elena invited them to live on her land, hoping they would care for her in return. When Elena began dialysis, Lucy would help, but after a year Lucy had a baby. Lucy now spends her time caring for her children or selling at market. She does not help Elena with chores or cooking, even though Elena often watches the grandchildren. 'Now they are bored with me, because I have been sick for so many years. Or maybe now they have more commitments'. As for her other family members, Elena offers that the demands of their jobs could keep them from helping her, though in another instance she declared 'it is because they have no love in their hearts: their hearts have hardened'.

For Elena, family support gradually waned in the context of an unresolving chronic illness. As the prevalence of chronic illnesses like CKD rises in Guatemala (IHME 2016), alongside

access to life-prolonging technologies like dialysis, we observe that family caregiving systems face, often for the first time, the need to sustain caregiving strategies for longer than they are able. Chronic illnesses strain relationships already encumbered by material scarcity, landlessness, unemployment (Manderson and Smith-Morris 2010). As we have described elsewhere (Chary and Rohloff 2015), families in rural Guatemala typically respond to undercare through the use of makeshift ‘tactics’, seizing opportunities as they arise and exploiting their social networks (de Certeau 1984). Dialysis poses a significant challenge to this improvisational approach by transforming ESRD from an acute catastrophic illness, during which family resources can be mobilized to provide temporary end-of-life care, into a depleting and extended effort of unpredictable duration.

In this setting, tactics may be exhausted, or competing obligations may arise that demand ‘a certain “selfishness” that pits individuals against one another’, as when Elena’s daughter turned her attention towards her new family and abandoned her mother (Scheper-Hughes 1992, 473; see also Biehl 2005). As illness drags on with dialysis ‘stretching the remainders of time’ (Moran-Smith 2012, 202), people may reach limits beyond which they are unable or unwilling to care for others. In these contexts, the use life-prolonging technology is an experiment testing the adaptive and responsive abilities of political systems and civil society. When bodily integrity so concretely depends on a deficient public health care and welfare system, the fragility of caregiving networks already stretched to their limits becomes apparent, exposing vulnerabilities just beneath the surface that families otherwise work so diligently to float above.

While on dialysis, Elena has watched her family members become ‘bored’ with her. She gets by on support from her church, neighbors, and charity organizations like ours, but she feels this is no replacement for care from her family. Likewise, Jorge was recently told by his wife and mother that they are exhausted with earning his bus fares. They tell him to either earn the fares himself or to move permanently to Guatemala City to live near the hemodialysis facility. Such a move would be unbearable for Jorge, as his primary joy in life is to be near his wife and sons; but the configuration of care that sustains his life has become unbearable to them. This is the essential existential uncertainty that characterizes living with dialysis within the system of undercare in rural, postwar Guatemala: How long will I live with dialysis, and under what conditions? Will our money last? Will my family continue to support me, and for how long?

## Conclusions

These cases of families living with dialysis in rural Guatemala show that ESRD demands a unique sort of caregiving due to its debilitating symptoms, lack of access to comprehensive

care, uncertain chronic illness trajectory, and time- and energy-intensive treatment. Dialysis requires people to regularly ‘leave their lives’ as Alma put it: thirty minutes multiple times per day for peritoneal dialysis, and perhaps an entire day of travel and treatment multiple times per week for hemodialysis, in addition to the labor required to fund these journeys. Dialysis structures the lives of users, their dependents, and their caregivers. As Russ, Shim, and Kaufman (2005, 299) write, ‘dialysis threatens to overcome and, for some patients, to become the life that it extends’ (emphasis in the original).

In Guatemala, the experience of ESRD and dialysis is shaped by a chronically under-resourced public health care system. Individuals whose lives are prolonged by dialysis still suffer debilitating symptoms like fatigue and weakness because they lack access to the resources, medications, and diagnostics necessary to alleviate those symptoms. During acute episodic illnesses, Guatemalan households often and effectively use short-term improvisational tactics to make do. However, in an uncertain chronic illness trajectory, these tactics must be sustained indefinitely, which may overwhelm caregiving resources and resolve. In these ways, dialysis care in rural Guatemala is bracketed by undercare that prolongs life while leaving unaddressed the capabilities of caregivers, overwhelmingly women, whose labors are rendered invisible and anonymous. Because dialysis care for the rural poor in Guatemala does not attend to caregiving networks – nor does it have the resources to support them – access to the technology can strain these social relations. Indeed, other authors have described how amid chronic scarcity, biomedical care may have unintended consequences, exacerbating conditions of poverty, straining social solidarity (Kalofonos 2010), and opening possibilities for abandonment by kin (Biehl 2012).

What we have shared about dialysis in rural Guatemala adds to a growing anthropological literature on ESRD and dialysis, and helps to illuminate how the experience of a technology may hinge on socioeconomic, cultural, and political context. For instance, exploring the lives of elderly patients on hemodialysis in California – who, like patients in rural Guatemala, are not candidates for kidney transplantation, though for very different reasons – Russ, Shim, and Kaufman (2005) describe how clinically sustained existence can reconfigure intimate relations and destabilize ideas of living and life. We build on these ideas by exploring the effects of medically delayed death in a younger population who are yet within the years of life in which they would otherwise be expected, and may still be expected, to care for others and earn wages. Living on dialysis, these individuals experience overwhelming relationship reconfigurations and identity crises that must be considered when offering these populations life-sustaining therapy in the absence of a curative endpoint like kidney transplantation.

Especially unsettling is that the dialysis treatment offered to these populations is inadequate, a partial treatment sufficient to stretch the remainder of life, but not sufficient to relieve fatigue, swelling, or nausea. As Moran-Thomas (2012) describes in Belize, the experience of

ESRD – defined by these debilitating lingering symptoms – is socially constructed by a state apparatus that rations essential therapies, the same apparatus whose disregard created the conditions for ESRD in the first place. Indeed, as Hamdy (2008) describes in Egypt, no dialysis patient is apart from regimes of medical treatment or state infrastructure, but rather is made physiologically dependent on the very systems implicated in ESRD etiologies. Especially for home-based dialysis, we extend this imaginary to include caregivers and partners whose unrecognized and uncompensated labors are essential to the success of decentralized dialysis programs. Indeed, as Moran-Thomas (2012) points out in her dissertation, chronic diseases like diabetes and ESRD are ‘para-communicable’, spreading along the same channels by which poverty and injustice permeate families and communities. Illnesses like ESRD are also communicable along webs of caregiving through which entire families and communities are drawn into technologically sustained, minimal existences dependent on partial treatments and hole-ridden state health and welfare programs.

Our intent is not to discount the importance of expanding dialysis therapies to rural areas of the world. These technologies allow people with ESRD to live years longer than they would have otherwise, years that may contain meaning and joy. Rather, we hope to inspire reflection about how life-prolonging biomedical technologies are experienced by people in places where social fabrics are already worn thin, by illuminating how life-prolonging technologies affect users and their kin and communities in different ways that may be harmful for caregiving networks. The notion of care tends to carry positive connotations: care is presumed to be a gesture of kindness and rescue. However, care can be harmful particularly when the locus of care is circumscribed to individual bodies, disregarding the ripple effects of illness and treatment, as is often the case in biomedicine. This reductionistic approach to health care is incongruent with lived reality in rural Guatemala: where lives are fluid, running together, across bodily boundaries and generations.

Life-prolonging, minimal care like dialysis care in Guatemala can strain those relationships that have been forcibly reconfigured around ‘partial treatment’ (Moran-Thomas 2012, 202). This undercare – care that attends to the end stages of disease, but fails to prevent disease progression; care that prolongs life, but fails to address the symptoms that diminish quality of life; care that demands a radical restructuring of the days that become weeks that become years in the lives of patients and their families, but without attending to or addressing the interdependencies of those lives – is care that is held and enacted in suspension, weakened and made fragile by the uncertain trajectories by which it becomes defined. Within the privatized, pluralized, and patchwork Guatemalan health care system, this existential uncertainty is compounded, perhaps leaving patients, families, and caregivers stressed beyond their ability to ‘make do’.

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