

Hawai'i to Hospice: Terminal Illness during a Global Pandemic

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Abstract

Using auto-ethnography, the authors explore their experiences with ALS during the COVID-19 global pandemic. With a focus on how the pandemic affected their lives, the authors explore disability, terminal illness, caregiving, the third shift, and the social construction of time.

Keywords: Caregiving, COVID-19 pandemic, Disability, Illness, ALS, Death/Dying, Marriage, Social construction of time, Privilege, Autoethnography, Qualitative Methods

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Introduction

On March 11, 2020, the World Health Organization's Director-General characterized the COVID-19 as a global pandemic. We were in Hawai'i; I (Sheila) prepared for a presentation at the University of Hawai'i. Despite Dan being almost fully paralyzed, we traveled to Hawai'i for the week with the assistance of Honolulu friends. Dan used an elaborate electric wheelchair to get around; he could still speak softly and slowly and eat carefully. All functional movement of his limbs was gone. He used three breathing machines on a daily basis to support his respiration. Dan lunched with a staff member from the Golden West ALS Association while I presented at UH. As I walked across campus to give my talk, I checked my email and my university made the decision, given the developing pandemic, to convert all classes to online after spring break. Then my phone rang—my colleague informed me that the University of Hawai'i also announced its plan that day to do the same. Attendance at my talk was slim.

On March 16, 2020, we flew home to Houston and entered a voluntary lockdown. My mom lives with us, and she prepared for our return. We canceled our home health assistance. We asked our friends and family not to visit. We stocked up on groceries and supplies. We were not sure what to expect—but we knew that if Dan

got the virus, given his compromised breathing, it would kill him. We also feared my elderly mother getting the infection. Fast forward to March 11, 2021; after coping with late-stage ALS for a year at home, sometimes with help and sometimes without help, our family decided to start hospice care for Dan.

My spouse, the love of my life, was diagnosed with ALS in August, 2018, just three months after we married. ALS, or "amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord" (ALS Association 2021). There is no cure for ALS, and it is 100 percent fatal. The average survival time after diagnosis is three years. ALS is sometimes called "Lou Gehrig's disease," after the beloved baseball player was diagnosed with it in 1939.

Dan was in marathon training shape at his diagnosis. He completed the Houston Marathon in January 2018 and qualified for the Dallas Marathon in December 2018. He had no other health conditions. Over the summer of 2018, we noticed his right index finger became stiffer each week and handwriting or holding a fork was difficult. His voice also changed, and he slurred his words, especially when tired. Last, he had muscle fasciculations (small spasms) on his arms. Three very minor symptoms that, when put together, became a diagnosis of one of the deadliest diseases.

Dealing with a sudden terminal illness diagnosis throws your life into disarray. We freaked out. It felt like being punched over and over and over again. Anytime we had to tell someone. Punch. Make a decision. Punch. Even to just think about it. Punch. We were a wreck, for months. But we coped.

Dan retired from his tenured position at the University of Houston—Clear Lake at the end of the semester he was diagnosed. We threw ourselves into traveling anywhere he wanted to go. His disease progressed slowly at first, but this last year, progress was quick. The theme of this article centers on how in a single year, we went from traveling the world to being homebound on hospice care. Terminal illness and progressive disability are hard enough for a couple to handle; however, the COVID-19 pandemic multiplied our struggle exponentially. We examine how we coped with the numerous challenges presented by ALS during the COVID-19 pandemic. In this article, the co-authors use autoethnography to explore disability, terminal illness, caregiving, career decision-making, accessing health services, and the social construction of time. We use our lens of living with ALS during a global pandemic to make broader statements about privilege and voice. We also explore how limited access to services and the denial of help and support caused by the pandemic.

ALS and COVID-19

During the pandemic, our lives changed dramatically. We were homebound and needed to be self-sufficient to provide for Dan's caregiving. We are privileged to have resources, income, and the ability to self-quarantine. I could do my job online and by Zoom. But the COVID pandemic stripped us of our help, support, community, and confidence in the medical world. We are not anti-science or anti-medicine—but science and medical research needed to focus on curing and stopping a global pandemic. Attention to rare diseases or terminally ill patients, understandably, took a backseat to the global emergency. My husband needed a surgery to prolong his life; it got delayed. And delayed again.

More than anything, the pandemic stole time from us. My husband's health declined each week—and at the beginning of the pandemic, we still traveled. His custom electric wheelchair was delivered in February 2020 and we bought a wheelchair accessible van. A "bucket list" trip to Ireland for a friend's birthday in June 2020 was cancelled. We planned to see more friends and family in our van that summer. Cancelled. We weren't ready to stop. He could still talk. He could still eat. He could still drink. He could travel. ALS robs people of these basic functions.

Dan's slogan for his experience with ALS is "Living out Loud," and we learned how to accomplish that in our home that year, as best we could. We started a public Facebook page, "Simplify and Cherish," to keep our friends and family updated about our journey. But we also used it as a writing space to remind ourselves of our core values as a couple: simplify everything in our life so that we can cherish the time we have together. Disability and terminal illness hid behind our front door, but these walls did not contain our whole lives. Our intellectual impact in this area speaks to and with the experience of many families living with a disability, a terminal illness, and caregiving during a pandemic.

Even the process of writing about terminal illness is affected by the illness. Sheila wrote the opening of this paper based on conversations with Dan and Sheila intended for an autoethnographic book about our journey. However, given the tight timeframe for submitting an abstract of the paper to the journal, I wrote the abstract alone. We intended to write the article together, but ALS robbed us of that opportunity. Denzin contends that "autoethnographic work must always be interventionist, seeking to give notice to those who may otherwise not be allowed to tell their story or who are denied a voice to speak" (2014:6). To give you a glimpse into Dan's voice, he wrote an autoethnographic essay started in June 2020 and finished in December 2020. Dan was fully paralyzed and had no use of his arms or legs. He wrote the essay on a special computer that tracks his eye-movements.

Coping, By Dr. Dan Haworth

*So useless to wonder why,
Blow a kiss and say goodbye*

These words, a lyric from the song "Deacon Blues" by Steely Dan, perfectly encapsulate the experience of living with ALS. It's useless to wonder why. Medical science offers no answers, only questions. We who live with ALS must content ourselves, indeed habituate ourselves, to this mystery. If it's useless to wonder why, all that remains is to work out how to live with an incurable, invariably terminal, illness.

There are no easy answers. One must accept one's own mortality. Yet this does not come easily, especially to someone like me. I am a scion of an old southern family that presumes it to be a birthright to live into your 90s. My Faulknerian upbringing, complete with an ancestor cult, venerated longevity. Add to that I did everything right—ate well, exercised regularly, and so on. Prior to my diagnosis I lived an active life. I guided multi-day backpacking and canoeing trips. I played soccer until age and injury

forced me to abandon the sport. Later in life I took up running, a sport I loved dearly. In all I completed over a dozen half marathons, two marathons, and multiple races at shorter distances. There are no magic bullets, no guarantees of longevity. All living beings eventually die. I must, and do, accept my mortality, albeit reluctantly.

Only in hindsight does the course of my disease become clear. I have what is classified as bulbar onset ALS. It declared itself suddenly. One afternoon as I was eating an apple, when the juice hit my palette, my epiglottis slammed shut. Thus I took the first step of my journey into the dark world of ALS. As of this writing, I am somewhere in the middle of my journey. I cannot say for certain. What I know for sure is that my body declines, bit by bit, little by little. My fingers curl so severely, a condition known as “claw hand,” that my hands have become useless appendages. The weakness of my throat muscles makes speaking and swallowing difficult. Mealtimes have become dicey affairs. So much so that I require a feeding tube. I rely on a powered wheelchair to get around. ALS has robbed me of my physical independence.

What remains is my mind.

I cling to this like a drowning man clings to flotsam. I have always cultivated a rich inner life. Books have been my constant companions. I speak fluent Spanish, and adore Spanish American literature. So, I live in my mind, utilizing the skills, habits, and talents that I honed en route to earning a Ph.D. in Latin American history. I have lived in and travelled extensively through the Americas. Memories of experiences nourish me. Moreover, writing liberates me from my physical limitations. Hence, writing about Latin America enables me to range far and wide across the lands that I love. What follows, then, gathers memories, observations culled from a lifelong fascination with the Americas.

Collectively, these essays¹ propose a new reading of the acronym ALS: A Love Story. They also testify to my undying love for my spouse, Sheila. Ferocious feminist, scholar, and activist, she makes my life liveable. Knowing her love buoys me as much as my love of the Americas. She gives me reason to live.

Dan died on April 9, 2021, shortly after the journal's editors accepted the abstract of this paper. I did not actually know if I could finish this article

¹ Dan is referring to the book that we are writing about this experience and that I am working on in

without him and in grief. But grief also imbues resolve, bravery, and determination. Our experience during the pandemic was unusual, but contains common aspects felt by families around the world. My intentions are to frame our experiences in a sociological lens and relate it to the research on caregiving and the social construction of time.



Caregiving and the Third Shift

Caregiving research focuses on three priorities of the person providing the caregiving: how they structure their employment, how they protect the person they are caring for, and how they secure resources to caregive (Weigt 2018). Women often are primary caregivers and take on additional roles during times of crisis. Many women during the pandemic took on significant extra caregiving, in addition to paid employment, and their usual work caring for children and households. Sociological research discusses these roles as “shifts” of work (Hochschild 1989). The first shift is paid work—usually full-time and outside the home. Women also work a second shift to care for the home, children, spouse, and domestic responsibilities (Hochschild 1989). During the pandemic, many women also worked a third shift. In many cases, this pandemic-induced “third shift” was childcare and helping their children with their online education. However, in my case, my third shift was Dan’s full-time caregiving.

When the pandemic began, we were so lucky to be able to have an accessible home and my mother to help us meet Dan’s needs as his body became more disabled. In early 2019, we sold our historic house and moved into a newer home that was wheelchair accessible and that we could renovate the bathroom to

2021 and 2022. I chose not to change that phrase for this article and to leave this essay as it will appear in the opening of that book.

be accessible as well. My mother moved in with us in April 2019, and her living with us helped tremendously. My mom is not a traditional mother by any means—she would not cook all day or clean the house. Her role was much more about companionship, emotional support, caregiving assistance, running errands, being another brain to help us make decisions (or fight the medical bureaucracy), and taking care of our growing zoo (her dog and our cats). As our family self-isolated in the early part of the pandemic to keep ourselves safe, my mother living with us provided emotional support and helped all of us feel less alone during a scary time personally and globally.

By early 2020, Dan needed constant caregiving. He was in a power wheelchair full-time. There was not a single personal care task that he could accomplish on his own (including feeding, drinking, taking pills, bathing, dressing, and toileting). His breathing declined, and four machines needed to be with us constantly to manage his respiration. He was not on an internal ventilator at any time but needed external ventilation support as he got weaker. As Dan's disease progressed, my roles multiplied. His voice and extremity muscles failed. I needed to "speak" for him, help him eat, and he needed more caregiving. This happened at the same time the pandemic began. As the COVID pandemic started in the United States, I needed to adjust my entire teaching plan while increasing my caregiving responsibilities. It took an intense situation and multiplied it. I was an Assistant Professor up for tenure, suddenly teaching my courses online, and engaged in more medical advocacy to get Dan's needs met during a global pandemic. I also became a full-time home health care provider, as we needed to cancel health assistants, nurses, and physical therapists coming into our home. I was also a daughter to a mother who had her own medical issues, the household financial bookkeeper, and a pet parent. It was my responsibility to keep in touch with our families and friends—they wanted to Zoom with Dan or talk to him on the phone, and we wanted to spend that time with them.

On one hand, our family was incredibly privileged that I was able to stay home and work online. I liked teaching on Zoom and thinking of ways to engage my students in this new situation. But it also took time and energy that I barely had. Dan needed 24-hour a day intense care. Someone needed to be by his side all the time. He was unable to call for help, ring a bell, or alert us in any way other than moaning.

Due to his disability, his illness, and the risk of COVID, all of Dan's caregiving needed to be met by my mother and me. However, due to her age, eyesight, and medical conditions, she was unable to help with several tasks such as the feeding tube, transferring Dan from bed to his wheelchair, or administering his

medication. Also, given the difference in relationship to Dan, I was responsible for showering him, toileting assistance, and I did the major cleanup work when he had accidents. I was so fried I could not function. Often, I did not eat all day, then ate too much at night. I drank too much wine late at night. I could not sleep. I laid awake listening to Dan breathe—or listened for him to moan to get my attention. If he needed to roll over, pee, or anything else, he was unable to call for me—so he quietly moaned. I slept so lightly so that I could hear him if he needed anything—but sometimes I still slept through his moans. I felt so guilty when I woke up to him after an accident or struggled to breathe. Caregiving became my third shift.

ALS is often managed through a "clinic" approach—which means that the person with ALS (PALS, as they are called in the community), along with their caregivers (CALs), spend an 8-hour day at the neurologist's office being seen by a team of doctors, clinicians, therapists, and other support personnel to help PALS and CALs deal with the disease progression. We were very fortunate to have access to two ALS clinics in the city where we live. We started at one clinic, but as we did more research about the disease, we realized the other clinic was one of the top clinics in the world. We switched to the clinic that was headed by an internationally renowned neurologist who designed the ALS clinic approach, Dr. Stanely Appel.

Each of our ALS clinics prepared us for the next stage of progression and tracked the course of Dan's disease. In a typical clinic day, we saw a neurologist (from Dr. Appel's team of 5 doctors). We also saw a social worker, the head nurse, nutritionist, physical therapist, occupational therapist, speech therapist, pulmonologist, a representative from the Muscular Dystrophy Association (MDA) and the ALS Association. PALS also undergo blood tests, breathing tests, mobility and dexterity exercises. We also met with the wheelchair technician, the eye-tracking tablet technician, and the breathing machine vendor. Often financial planners, estate lawyers, and representatives from a wheelchair vehicle vendor were on hand if anyone needed free help. At the end of a clinic day, we were exhausted but well informed on next steps.

Dan could not feed himself after the muscles in his arms and hands became too weak to lift a fork to his mouth. I took over feeding him in fall of 2019, and we learned in early March of 2020 that he needed a feeding tube. His operation was scheduled for late March when we returned from Hawai'i. It got cancelled the day after we returned home. Eating was difficult because the muscles in his mouth and throat weakened more each week. He choked on almost every bite. ALS is a calorie hungry disease, and along with Dan's fast metabolism, getting enough calories

into his body was a major struggle. We put sour cream, butter, or melted cheese on everything. He drank more smoothies than I can count, all with added protein powder, and ate ice cream by the gallons. We did anything we could think of, and anything the nutritionists at the ALS clinic suggested. Friends and family sent treats for him. He kept losing weight. By the time his feeding tube surgery was rescheduled for late June 2020, he was below 160 pounds. At 6 feet 2 inches, and losing muscle mass daily, this weight was far too low for him.

The day before we left for Hawai'i, we attended ALS clinic in March 2020. The timing was fortunate. One of the major changes to Dan's health care during the pandemic was that the ALS clinic was cancelled, and, when reinstated, it changed. PALS spent the entire clinic day in one room, and a limited number of doctors and therapists came. Usually, clinic is a very social experience. Part of the benefit of this clinic approach is meeting other families in the open waiting room and the social interaction provides support for your family. During the pandemic, the isolation we felt at home was mirrored by the adaptations to the clinic approach designed to keep a very vulnerable population safe. Sitting alone in an exam room all day was more tiresome and very boring.

Instead of ALS clinic in June 2020, Dan finally got his feeding tube. The operation, which is typically an outpatient procedure, was done at the hospital that his ALS team was based. He stayed overnight for 2 nights, and the team visited him in his room.

The ALS clinic in September 2020 was the first one we attended after the pandemic began. Our team assured us that we could restart home health care services. The medical community understood the virus and transmission enough to know how to keep people safe during medical and health interactions. We were so relieved. We needed our home health aides; my back was in so much pain from lifting Dan. We also had several close calls around falling, because my back was not strong enough for the load we needed to bear. My mom's spine, hips, and knees were also in a tremendous amount of pain from helping me lift Dan. As his body got weaker, our bodies wore out as well. We needed more support—but we struggled with how to keep him—and mom and I—safe from the virus if people came into our home several days a week.

We finally restarted home health care in October 2020. Dan was not opposed to someone coming twice a week to help him shower. He understood that it gave me a break. Dan was six feet, two inches tall, and I am five feet, four inches. Lifting and moving him, transferring him from the bed to the shower wheelchair, dressing him, and transferring him to the power wheelchair took all my strength. I still needed assistance from my mom. Further, he was weaker each

week; the muscle strength in his arms was totally gone. His ability to help with the transfers or put his arms around me while I lifted him declined each week. By March of 2021, Dan needed two shower attendants, myself, and a power lift to get him from bed to the shower wheelchair, dressed, and into his power wheelchair. Every joint in his body needed supporting, including his neck. The services the home health aides provided were essential to Dan's health and cleanliness, my health, and my mom's health. By helping Dan shower, shave, and brush his teeth, the health aides gave mom and I the space to take care of other duties. We changed the bed while he showered. The laundry was never ending.

A central question I asked myself during this time was, "is this task worth time away from Dan?" Besides required activities from my university, my department was supportive, taking responsibilities off my plate while I cared for Dan. By the midpoint of Spring semester, 2021, I was a wreck. I was coming apart. My first, second, and third shifts overlapped, never ended, and overwhelmed me. I taught two classes online and my students were stressed out too. I was often interrupted during my synchronous Zoom classes to help my mom with Dan as he coughed and choked for air. My teaching assistant was amazing. She and I worked out a system so that if I suddenly needed to run help Dan for a moment, she had discussion questions ready on that day's material to facilitate a discussion with the students while I was gone. I was open with my students both during the Fall 2020 and Spring 2021 semesters about my situation. I knew I would be interrupted during our sessions—there was no way to avoid it given Dan's health and our lack of a full-time nurse or health aide. My students—and my TAs—were so compassionate about the situation. I did my best, and they did theirs. Some days just fell apart—but we learned more in my courses than just Sociology of Gender (or poverty). We learned together how to cope with life's impossible moments, how to deal with unbearable stress, and how to prioritize during a global crisis. Mostly, we learned how to be compassionate to one another. The work they submitted was mostly decent. I stopped caring about exact deadlines. I wanted them to do their best, let my TA and I give them feedback, and then work to make it better. We all worked many "shifts" during this time, and my focus was my third shift.

During my process of caregiving for my beloved husband, everyone told me, "take care of yourself!" Helpful friends, family who lived thousands of miles away, people on Facebook, my colleagues, our doctors, my therapist—everyone. But *how* do you do that when your spouse is fully paralyzed, works for every single breath, cannot speak, while you are working full-time online via Zoom, during a global

pandemic. It was impossible. No matter what we tried, I was fried all the time. My mom was too. I often walked into our garage, grabbed a bottle of water (or a glass of wine) from the garage fridge, leaned against our wheelchair van, and just cried. I even kept tissues out there. If I didn't cry, I stood in the garage, speechless. Sometimes I screamed. I didn't do any of it in front of Dan. Our backyard is beautiful, but the master bedroom backs up to it. I learned early in our journey not to talk on the phone, cry, or yell back there—because Dan heard every word. He worried so much about being a burden. I tried to console him and assure him that he was not a burden, but we both knew his condition took an intense toll on all of us.

We often listened to NPR while we slept or napped. On a show one day, Kate Washington came on to talk about her new book, *Already Toast: Caregiving and Burnout in America* (2021). I laid there in bed and listened attentively; I realized I was silently crying. Tears rolled down my cheeks as I listened. Her experience and her voice echoed the struggles I experienced. Even the title of the book made sense to me. I was already toast. My third shift shattered me.

The Social Construction of Time

During the pandemic, time warped. I know many people felt this time warp, but ours also warped due to terminal illness. Charmaz writes about good days and bad days when dealing with illness—and how time is measured by those swings (1993). We measured our time and days by how Dan felt—if he wanted to get out of bed, if he felt like zooming with family, who came to our house, or if I taught. Many times, during this process, we lost track of what day of the week it was. I knew what we scheduled for the day—shower aides or a nurse visit, physical therapy, or teaching on Zoom—but not what day it was. One day mom and I had a funny argument about if it was Thursday or Friday. It was Tuesday. A family member sent us a clock with the time, day, and date. A hilarious, but also, much-needed gift.

Celebrating Dan's fiftieth birthday on January 9, 2021, is an example of all the concepts discussed here. Before ALS, we started to plan an amazing vacation to invite friends and family to come with us. Dan loved being on a beach for his winter birthday. After his ALS diagnosis and our first trip to Hawai'i, Dan decided he wanted to go back for his 50th. He had so much fun; we figured out how to make the trip accessible with his power wheelchair. He invited friends and family to meet us there. A group bucket list trip! Despite the COVID lockdowns, travel restrictions, and risk to being around people not in your household, we booked and paid for our trip. We hoped by January 2021, the

risk would be minimal enough to travel. Nope. So, we pivoted. We live in Houston, Texas and the beach at Galveston is nice in the winter. I started a search for a wheelchair accessible room with a view of the Gulf of Mexico. The rest of Texas decided to party with their families over the holidays—and by January, COVID rates were spiking again in our area. Too risky. Pivot.

I booked a nice hotel downtown (about 1.5 miles from our house) with a fancy heated pool. Dan could swim with the assistance of myself and his regular physical therapist (who we asked to come to the hotel on Dan's birthday). We rented a cabana and invited our friends for an outdoor birthday toast. Then, of course, the weather interfered. It was warm enough for Dan to swim. Further, our home health care was compromised if we missed an appointment; Dan was no longer considered "home bound" and I would have to start the paperwork over again to get services restarted. So, something as "simple" as going to a hotel downtown or on Galveston (40 miles) for a couple nights cancelled his home health and physical therapy for the next couple weeks. This was not a risk our family could take. Fourth pivot!

With less than four days to Dan's birthday, I emailed and called our local friends, Dan's running club, and a photographer. We planned a car parade and an outdoor driveway party, complete with custom printed koozie can covers. I reached out to friends and family from around the world to send me birthday wishes that I printed out and made into a banner. I ordered fiftieth birthday paraphernalia and decorations on Amazon. Our closest friends came over early to set up. Dan knew we had family pictures scheduled for his birthday—but the parade and party was a surprise. He was up and out of bed, dressed, and the photographer came inside with a mask and took pictures. Then we went outside, and the car parade started. His face glowed all day. Overall, the day was amazing! We kept Dan at home, safe from COVID, and our friends celebrated with us. When he got tired, we moved him back into bed with all his equipment. The home parade party was lovely, but it was plan D in the pandemic.

I spent countless hours trying to figure out how to make Dan's big birthday special given the constraints of his illness and the pandemic. Our community supported us in any way they could—mindful of their and Dan's safety. We knew it was likely Dan's last birthday, and we made it special and memorable.

During the late fall and spring of 2020-2021, I left the house for 2-3 hours once or twice a week to pick up groceries, go to the pharmacy, and to take a break. I enjoyed a glass of wine, some wings, and alone time at a handful of favorite outdoor restaurants/bars close to the house. During this time, I tried to read several books to help me cope with my situation. For example, *The Conscious Caregiver* by Abbit discusses ways in

which to avoid burnout, care for loved ones at home, and understand anticipatory grief (2017). This amazing book is intended for adult caregivers of their elderly parents—and the frame often was confined by that intended audience. However, Abbit recognized issues that sociologists call the third shift and how to cope with burnout. Yet, the pandemic and resulting isolation made many of the suggestions impossible to use. I also read neuroscience and psychological research on resilience. Hanson's *Resilient* (2018) is excellent—however, I struggled through a nightmare. It was difficult for me to focus on being resilient when all I wanted was a full night of sleep. Again, these books helped me cope, but I wanted to throw these books as far as I could and scream. I longed for a cure for ALS so that I did not watch the love of my life die from a horrible disease. Anyone who told me “life will get better soon” did not understand that the only way my situation could get “better” included my beloved husband dying. A heart wrenching thought. I finally gave up trying “self-help” books to help me cope and turned to fiction. I did not have much time and had trouble with my attention span for reading for pleasure, but when I did, action fiction seemed to help me more than the best-intended books.

The Wednesday of the week before spring break in March 2021, I was burned out, crying most of the time from pain and frustration, and so exhausted I could hardly see. I needed us to start hospice services for additional help. We talked about hospice for months—trying to get Dan used to the idea of hospice without bursting into tears. Him crying caused me to burst into tears. When I finally called hospice, I was on the edge of a breakdown. Dan was very sick—sicker than we even realized at the time. The initial intake took two hours by phone. The next day was a two-hour visit from a nurse. The third day was another three-hour visit from a different nurse. I called hospice when I was at the end of my rope balancing caregiving, working, and my own health. But to complete the hospice intake process, I dug even deeper, and more exhausted than I have ever experienced, I worked through another layer of medical bureaucracy, advocating for my spouse, and decision-making with my family. We negotiated and pushed hospice to ensure all the services our family desperately needed.

Three weeks after we started hospice, I followed our hospice nurse out our front door to talk to her privately in the driveway. I asked her “the” question—how much time do you think he has? She looked at me—took off her sunglasses and really looked at me. I started to squirm in the early spring heat. She said, “what do you think?” And looked at me hard. “Uh? Umm? A couple months?” She hugged me. Patted my back, then my arm. She pulled back and said, “I have never had an ALS patient for more than 2 months.” I

swallowed hard, straightened up my back, and tried not to panic. Or scream. Or run away from an inescapable grief that hit me as hard as his diagnosis did. “Ok. I appreciate your honesty. And your support.” Dan died a week later.

Privilege

Throughout our experiences of the last year and a half, the role of privilege is evident. In my research and writing, I use an intersectional lens to understand participants' and my own experiences (see Hill Collins and Bilge 2020). Notably economic, heterosexual, educated, and white privilege helped our family. Dan and I both had a lifetime of decent health care and no disabilities before his ALS diagnosis. We benefitted from class and heterosexual privilege as we grappled with bureaucracies to meet Dan's needs. I sometimes intentionally invoked Dan's level of education or my own when dealing with medical professionals. Just because he slurred his words due to ALS, it did not mean there was not a sharp mind behind it. Even in those moments, I knew I used our privilege to access the care he needed or our family the resources and support we needed.

We used and acknowledged our privilege in this process. Our family and friends supported us financially, with treats, Amazon wish list items, travel support, and in countless other ways. Our social support network was engaged and strong through our journey. We navigated accessing health services, working from home, using our social support network, and engaging with friends and family through technology (such as Zoom or Dan's eye-tracking computer). Telemedicine is now a more widely accepted option and needs to continue to be. With Medicare covering those services now, it is easier for the disabled and elderly to access medical appointments online instead of needing to go in person. However, we still struggled deeply because of the pandemic and trying to keep our household safe from the virus. We often wondered and discussed as a family—if we were struggling this deeply, imagine other families in our situation who didn't have work that could be done online, a third adult living in the household, economic resources, supportive friends and family who could be flexible to our needs—how were they coping?

Conclusion

As an ethnographer and qualitative researcher, I believe in the power of telling stories. Telling stories helps people cope with our lived experiences. As a sociologist, I look to situate those experiences in the

academic research on the issues. The COVID-19 pandemic took a massive toll on daily life—from those who got the virus to those who did not—but we all experienced the global health, economic, political, scientific, education, professional, and personal changes it necessitated. Writing about my experiences with my spouse and his illness and disability during the pandemic helps me personally cope with my loss. I hope this piece also helps situate issues of caregiving, accessing health services, disability, and privilege in our research literature on the pandemic.

A final personal note. As I submitted the first draft of this article in August 2021, my mother was diagnosed with Stage 1 breast cancer, a different type in a different breast than the cancer she survived in 2007. Her surgery was that week. She had knee replacement surgery in November 2021. She is now doing well and the caregiving journey continues. She and I used the 2021 summer to rest and grieve and recover from the exhausting last year. I read *Wintering: The Power of Rest and Retreat in Difficult Times* by Katherine May (2020). We “wintered” during the rising Houston summer heat. We celebrated her 73rd birthday at the hot air balloon festival in New Mexico. We are strong and will continue our journey together. And I’ll keep writing about it.

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Author Biography

Sheila M. Katz, Ph.D. is Associate Professor of Sociology at the University of Houston and Women’s, Gender, and Sexuality Studies affiliated faculty. She earned her M.A. and Ph.D. in Sociology from Vanderbilt and B.A. in Sociology and Women’s Studies from the University of Georgia. She uses qualitative research to understand women’s poverty and experiences in domestic violence, accessing health and human services, activism, and education. As a scholar activist, her work is applied, feminist, and intersectional. Her first book, *Reformed American Dreams: Welfare Mothers, Higher Education, and Activism*, was published by Rutgers University Press in 2019. She lives in Freedmen’s Town of Houston, Texas with seven cats, a mom, a dog, and a garden to tinker in while drinking wine.

Daniel S. Haworth, Ph.D. was Professor Emeritus of Latin American History at the University of Houston—Clear Lake. Dr. Haworth had an undergraduate degree from the University of North Carolina at Chapel Hill with double majors in History and Spanish. His master’s and

doctorate were in History from the University of Texas at Austin. His research focused on everyday life in nineteenth-century Mexico and he has published in both Mexico and the United States. He was a Fulbright-García Robles grantee (1998-1999). His research concerned the intersection of family life and public authority in the lives of adolescents. During the summer of 2018, Dr. Haworth spent 10 weeks in Guanajuato, Mexico getting married to Sheila and finishing the data collection for his academic book, *Growing up in Guanajuato*. He was invited by the State of Guanajuato legislature to give a presentation about the historical figure Manuel Doblado, in honor of his 100th birthday. Dr. Haworth was the founding director of the Latina/o and Latin American Studies (LLAS) program, and in that capacity oversaw the creation and implementation of the LLAS minor. He was involved in establishing Spanish language classes at UHCL and enhancing partnerships with Sueño Latino student organizations at area high schools. In his teaching, Dr. Haworth was a generalist, offering undergraduate and graduate courses on an array of Latin American topics. He promoted international studies at UHCL. He aimed to advance awareness of the Latin American past and present.