Randall Reitz Laura E. Sudano Mark P. Knudson *Editors*

Connections in the Clinic

Relational Narratives from Team-Based Primary Care





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Randall Reitz · Laura E. Sudano · Mark P. Knudson Editors

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Relational Narratives from Team-Based Primary Care



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ISBN 978-3-030-46273-4 ISBN 978-3-030-46274-1 (eBook) https://doi.org/10.1007/978-3-030-46274-1

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This Springer imprint is published by the registered company Springer Nature Switzerland AG The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Randall to Ana
We run through life
Round the same lakes
I push the gas
You pump the brakes

Laura
For those before and after me.

Mark to Jenni who has shared a life, taught me about life, helped me weather the hardships and appreciate the joys of life, and blessed me in supporting the lives of 3 amazing children.

Preface

I'm often drawn to write haiku about the constellation Orion. I usually phrase these thoughts as anthropomorphic salutations to the heavens:

Body, limbs, belt, bow May your lasting grit and grace Guide my path today

I've reflected on why I do this with Orion, but never with other equally beautiful patterns in the stars. I've arrived at 2 conclusions: First, I prefer Orion because I have imbued within him many of the values and strengths that I desire for myself. But, perhaps more importantly and more basically, I identify with Orion because I can identify Orion. Of the billions of stars visible in the night sky, the pattern that we call Orion is one of the few that I have internalized. I trust that during the winter months, he will always be overhead in the early morning.

Gentle Orion
Float above the wood stack
Light my home this dawn

This doesn't mean that other stars or patterns are less visible or less striking. It simply means that I don't recognize them as patterns. While others see dragons, scorpions, dogs, and bears in the sky, I've only made sense of the seven or so stars that we call Orion. I have come to connect these dots in a way that renders them memorable and meaningful to me. I have created and recreated a personal narrative around these inanimate objects.

Orion hovers south
Then fades in the blaze of the
Grand Mesa sunrise

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This is the power of narrative. Our daily life is so full of events and observations that we are unable to assimilate all of it. As a result, we create shortcuts to help us make sense of the deluge of data. Over time, these connections take on a meaning of their own and result in a story that explains the importance of what was previously a random assortment of events.

Perhaps more importantly, if we fail to create connections between the stimuli of our 5 senses, then in a very real way, the stimuli never happens. Events that aren't connected into narratives are easily overlooked as random occurrences. But, when we encircle them within a story, we find meaning in them and wisdom for how to approach a similar constellation of information in the future.

Connections in the Clinic is an attempt to find meaning in the relationships that are created in team-based primary care. These stories and images aim to help us make sense of the more poignant experiences in the clinical context and of the events outside the clinic that shape our approach to health care. Without collecting these narratives into one volume, we would each only have one or two constellations to make sense of our experiences. But, by collecting and organizing them, we begin to recognize and appreciate the full diversity of the patterns across our lives.

I hope that reading these stories will inspire your work and relationships.

Grand Junction, USA

Randall Reitz

* * *

This book is as broad and grand as the constellations above us, encompassing the expanse of the human condition from birth to death. Yet it is also as specific as the relationship between 2 people, which we experience in caring for others. We hope readers find meaning in this scope of stories, and in the emotional reflection that is captured in each of the narratives and poems.

As the first submissions for this book were coming in, I experienced the death of a dear 91-year-old patient I had cared for over 20 years. Her last weeks of hospice care were full of daily interactions with her and her daughter from England. The sadness of loss was profound, as our "doctor—patient" relationship was complex and atypical. From the start, my quiet professionalism was greeted with her argumentative combative style. She challenged every medication I proposed, questioned every diagnosis I considered. But I slowly learned that she valued my role, and would take the medications or follow up for the tests she had argued against.

In her last weeks, she softened greatly, reflecting on the medical care we had shared. One day, she looked at me and said, "For years you have heard my complaints, listened as I bragged about my daughter, sat quietly as I railed about politics, and looked with interest on the pictures I shared of my 2 grandchildren.

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Now that I am almost gone, it's time for you to tell me about you!" We spent the next half hour, talking, and she attended to every word of my story about my family, my struggles, and my joys. She teared up when I told her of my child's battle with death the previous year, interjecting, "I remember last year, you seemed both distant and more compassionate than I ever remembered. I feel selfish for not realizing that when I had pain, I was not always alone."

Yet in her last days, she kept her sense of humor (sarcastic, ironic, and sincere). In an email she sent a picture of her hospice dinner: pureed asparagus and lime sherbet. "They won't have to wait until death for my body to turn moldy green!" She also retained her authoritative style, telling me that I should spend more time writing. We had shared a love of poetry by Philip Levine who died that February. She sent me the New Yorker, dedicated to him, with admonition that he gave up a good career in Detroit to become a poet. "If Medicine doesn't work out, maybe you could go to lowa, and learn to write. I am certain that I have given you a few decades of stuff to write about!"

Months after her funeral, I found myself at a local cemetery one winter eve, and realized she was buried there. I teared up at the thought of her death. I struggled with the larger issues of loss. And then, I was reminded of her energy, her enthusiasm, her sarcastic and pervasive sense of humor, and I realized that she was not turning green in a pine box buried there. Her spirit lived on, to enliven those who remember her.

Untitled

Frozen fiddle strings of icy air, high pitched and tendril thin, found their way thru button hole, up cuffs and down collar past heavy scarf.

Standing on the hillock of dead grass,
black sky with paucity of stars
was no longer a blanket of darkness,
but instead an empty door to the cold and vastness
of the universe.

I looked back,
across thousands of granite markers
and imagined the fresh earth that covered
pine boards,
remembered the last shovel of dirt
and the hollow sound it made,
imagined the loneliness and emptiness
of a thousand boxes,
and knew that you were in none of them.

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We hope that our readers find a pause at these stories and poems that explore our interactions with those we heal, our relationships with mentors and family who teach and guide us in our healing art, and our introspections into who we are as healers. We trust that many of you will make it a regular habit to explore the narratives and poetry of other healers, and that some number of you might be inspired to use writing as a powerful reflective tool of your own.

Winston-Salem, USA

Mark P. Knudson

* * *

What just happened? I thought, after hanging up the phone with my mom. "He left you to die," and described, "When you opened the door, you looked like death." There was a coordination of care, an understanding that my husband needed to return to work after being with me for those few weeks in the hospital being treated for what was thought to be viral meningitis. It turned out that I had contracted a bacteria that destroyed my heart valve and distributed emboli on my vital organs, including my brain.

She just shared her account of my near-death experience. Her re-telling of the story, however, was not my story. In fact, it wasn't my experience at all. Her truth was not my truth, but it was her truth nonetheless.

But what was my story? How could I articulate what happened to me during the course of my illness? The medical complications, the medical team's care, and the family conflict? Better yet, how could I make sense out of this nonsense life event, and how did it change me—my approach to patient care, education, and relationships?

This is what narrative medicine means to me. That I can integrate an experience I had into my identity as a person, a professional, through the use of storytelling. This mixing allows for one to reflect and describe the experience. The reader is exposed to the story, and sometimes the wisdom and knowledge that the events inspired in you become exposed in a way that the reader may share your wisdom and knowledge.

After my medical experience, I considered how we can invite others to share experiences such as these and how we can use them as educational tools. I approached, or more like cornered, Randall after a plenary session during an annual conference and asked him if he would be interested in developing this idea. The training of healthcare providers, the awareness of treating the whole family, and the healthcare landscape has changed since the edited book, The Shared Experience of Illness (McDaniel, Hepworth, & Doberty, 1997). But how far have we come in implementing best practices and affecting change?

Preface xi

Storytelling is unique in that we, as humans, can express it through art or language. Some say that storytelling is as old as time. One of the first accounts of storytelling can be traced back to somewhere between 15000 and 13000 BC. Children in the Pyrenees Mountains found drawings of over 2000 figures with elements of a narrative (Lockett, 2007). Homer's epics are a popular example of storytelling, which were originally told by Homer around 1200 BC and were written about 700 BC.

People tell stories and listen to them because there is conflict and some sort of resolution, albeit painful at times. And through that, they see the knowledge gained and sometimes that knowledge resonates with them, and they carry that knowledge home. Told right, storytelling doesn't tell you the lesson learned. It shows you.

These narratives shared in this book, along with its images, will hopefully inspire you to integrate your experiences and create your story so that one day you may share your truth with someone.

San Diego, USA

Laura E. Sudano

Acknowledgments

This book shares stories of relationships—some good, some bad. We're fortunate to have benefited from many good relationships—many of which are similar to those described in the chapters of this book.

Teachers and Mentors have guided our professional development, helped us to avoid mishaps, and helped us to clean up when we didn't avoid them. Randall wishes to acknowledge Wendy Watson, Steve Hurd, Larry Mauksch, Colleen Fogarty, Jeff Ring, and Deb Taylor. Laura wishes to acknowledge Randall Reitz, Mark P. Knudson, Richard Lord, and Jo Ellen Patterson for their steadfast support. Mark wishes to acknowledge Robin Blake who first introduced him to literature and medicine, and Paul Gross and everyone at Pulse, who have nurtured the love of narrative medicine.

Family is our first social foyer in which we learn connection with others. We are grateful to our families of origin and families of creation without whom we could not be self-reflective and grow.

Patients are what drew us to our occupations, as we dreamed of helping others. But somewhere along the path of providing care, we realized that patients were our ultimate teacher, baring their souls to us to give us an understanding of the human condition, and helping us to realize the important healing power of the shared, spoken, and written word.

Colleagues and Collaborators have blessed us across our careers and helped to make this book possible. We'd like to send our appreciation to the authors and illustrators who undertook this process with us. Your lives, stories, and your ability to write stories about your lives inspire us. We are all medical educators and have been blessed with excellent faculty colleagues and trainees. You have enriched our days and helped us to contribute to the scholarship and workforce of our fields.

And finally, we want to express our gratitude for the great support from the staff of Springer Publishers.

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Artist Bios



Kat Gray BS is currently a stay at home mother of two. She graduated from Colorado Mesa University with a bachelors degree in psychology in 2011. Kat had focused her love of art and psychology together while working as the activities coordinator at West Springs Psychiatric Hospital for six years before starting a family with her husband. Outside of caring for her children and home, Kat enjoys painting, drawing, baking with her children, and tribal belly dance. Her artwork is found on pages 70, 263, 277, 292.



Luke Woody is an illustrator, designer and creative director from Austin, Texas. With pen, ink and other media, he distills complex themes into simple, striking visual stories. His artwork is found on page 139.

xxii Artist Bios



Sabrina Motta RN BSN is a school nurse with Mesa Valley School District 51, previously employed by St. Mary's Family Medicine Residency as a triage nurse. Her background in medicine started as a reservist and volunteer firefighter EMT-Intermediate with Durango Fire and Rescue. Outside of her career in medicine she works as a freelance artist and enjoys mountain biking, swimming, skiing, camping, and rafting with her family. Her artwork is found on pages 44, 95, 140, 194, 250, 296.



Yvette Campbell is a painter, hiker, and biker who lives in Grand Junction, Colorado. Her artwork is found on page 268.



Electronic supplementary material The online version of this chapter (https://doi.org/10. 1007/978-3-030-46274-1_1) contains supplementary material, which is available to authorized users.

Aunt Peg

Colleen T. Fogarty

The taciturn aunt, no children of her own

Taught me pie-baking when I was young.

Once, I bumped the tin Berries scattered everywhere. A scolding; No pie for me

Tears started— Wait….

Gathering the berries, she gently washed them, Helped re-shape the dough.

A vivid lesson—
perseverance, second chances,
and even—
the importance of forgiveness.

Different Fathers. Different Sons.

John G. Spangler

The photo is old and yellowing, curling at the edges, crinkled across Kodachrome color.

It's 1962.

You are in sky blue overalls with a white shirt and white, toddler shoes. You sit on your weary father's lap. He is beginning to bald and wears tortoise rimmed glasses, so much younger than you ever remember.

You are facing him. He is falling asleep, tired after a long shift as a third-year radiology resident.

This is the first father and son photograph you knew. You did not know him well in those early days of residency, and the first years of junior partner at the community hospital in your hometown.

Even in middle school, your days began at 6:00 am, swim practice or splitting wood; his days started with an early intravenous pyelogram. You did not enter his world often, and in those days, he rarely entered yours.

He was always on call, you see. With only 1 phone line at home, and no beepers back then, the phone was off limits with the exception of a 1-minute rule. "If you *must* make plans, go ahead." But a minute is not long enough for friends or plans or dreams.

Sometimes, if you were lucky, you would ride with him on Saturdays to the hospital and explore as he read out weekend films: The Wards, The 1-room Emergency Room, and The Door to the Morgue. At least, as the youngest, you had these special times with him.

So at a young age, you could discern the right and left hemidiaphragm, recognize a thyroid scan with a cold nodule, "diagnose" a broken bone—which he sometimes asked you to do.

Looking at a radiograph together, he would say, "What do you think is wrong with

this leg?" The compound fracture would be obvious, even to you.

At home, you had scalpels, and syringes, and sutures and needle holders for sewing up a slit orange, or a ripped blanket. You had a chemistry set.

He brought home lead containers for you that had held radioisotopes at the

You must understand, your mother counsels. Doctors were different back then. Unquestioned. Life was dribbled out by him to you. You pretty much just had to accept that as your filial duty.

Department of Radiology. You melted these down over a homemade Bunsen burner and spilled liquid metal into cold water to make wonderful, globular creations as the lead instantaneously re-solidified.

He placed radiation in tumors. Today, you wonder having been exposed to radiation residue and leaden fumes.

You dream at that age that you will be a physician, just like him.

As you progressed through college and medical school, somehow you could relate better to him. He understood straight A's, \$1.00 apiece. He understood Phi Beta Kappa, a \$500 reward. As you began to grasp his world, you could share these single things together, like a conversation.

Late one night during your own residency, in the dark corridors of Johns Hopkins Hospital L&D, your own son is born. You saw many births at the county hospital as a third-year medical student. You delivered them yourself at that impressionable age.

You are accustomed to the acral cyanosis of those first moments that flush pink with the lusty cry of full newborn lungs, shaking off the shunting, shutting off the ductus.

But this birth is different. The doctor hands you your 6-minute-old son, Apgars 8 and 9. He has big, black searching eyes, as if he is scrutinizing your face.

He has your hooked big toes.

Your firstborn son! The night passes like a dream.

He's 1 of 6 of your brood of children. You enter their lives with gusto, as if to compensate for your own childhood.

You take call nights and do diapers. Discharge patients and rush home to help with dinner, bath, and bed. Every chance you can—you live 5 blocks away—you hurry back for lunch.

Is it for you? Your wife? Your own youth set ajar? Or for your 6 that you lunge your whole being into their lives like your father could barely dip his big toe into yours? You must understand, your mother counsels. Doctors were different back then. Unquestioned. Life was dribbled out by him to you. You pretty much just had to accept that as your filial duty.

Yes, Sir, Lieutenant!

But times change, and with this different time come different fathers.

Preparing for boards last month, your son with your toes came home for the last few days of STEP 1 study. You quizzed him on Roth spots and Koplik spots and Rocky Mountain Fever spots.

You didn't remember the classes of antiarrhythmic medications. But your Apgars 8-and-9 son does—which he explained to you carefully and mechanistically and in detail the indications, contraindications, and side effects.

And tonight is his first night on call as a third-year medical student.

He texts you:

Him: Peds neuro 6 wk old late onset meningitis Group b strep

You: Recent cheese outbreak here Listeria

Him: Rx that with ampicillin

Of course, he knows that. You smile.

You: Yep good luck tonight love you

Him: Love you too

You know he is well on his way.

Cat Stevens laments in *Father and Son*: "I was once like you are now, and I know that it's not easy to be calm when you know something's going on."

Your father was once like you. And you were once like your son.

But you are different fathers, and you are different sons—

Each with different dreams, yet each with the same old, new perspectives.

Donuts in the Cemetery

Alexandra Schmidt Hulst

Touchdown in Dallas. The familiar overhead ding sounds and passengers lurch into the aisles, stretching and yawning and clamoring off the plane into a muggy Texas September afternoon. I breathe in slowly, gather my bags, and quickly shed my fleece sweater. My husband of 4 months squeezes my hand as we exit the airport, giving me a small, reassuring smile.

An hour later, we walk in the door of my grandparents' house, and I think "I am home" as I inhale the familiar smells of 65 years of raising 9 children, cooking for family, and countless dogs. As I quickly gaze out at the lawn and around the familiar hallways of this old house, I think of spring mornings searching for Easter eggs with my cousins, lazy rainy afternoons watching squirrels scurry through the ancient trees, and jam packed Thanksgiving dinners full of boisterous laughter and football blaring from the den. "Deep breath," I think to myself, swallowing down sadness as a quick round of hugs begins. Family has arrived from Atlanta and Boulder and Cedar Rapids as we prepare to say goodbye to my grandmother on this Labor Day weekend. Though the house is full of people, it feels more empty without her here.

Click clack. The slow sound of shoes stepping gingerly across the tile floor of my grandparents' church. More hugs, more family arriving for the visitation and the rosary. My husband whispers to me, "Do you think you'll cry tonight seeing her?" I shake my head naively, thinking that it won't feel real that she's gone until I see her casket being laid in the ground. As I think of how her lungs used to torment her as she gasped for air in the final months, I whisper back, "We saw her 3 weeks ago. I said what I needed to then. I'll be ok. I'm thankful she's not suffering anymore." He gives me a quiet look of I-know-you're-wrong-but-I-won't-say-it. Wise husband.

Seeing my grandmother's face—so familiar and so foreign—in the casket does bring me to tears, surprisingly and not surprisingly. More powerful than this is the way my heart simultaneously breaks and heals by watching my family grieve: quiet sobs, heaving shoulders, stifled sniffles, tight embraces, sad smiles shared across the aisle. I think to myself, "I love these people. My people."

The next day, we celebrate a funeral Mass for Shirley Marie Uhrik. Mother of 9. Wife to Richard Uhrik for 63 years. We sing How Great Thou Art, we soberly file out of the church, and we drive over in a long line to the cemetery. The priest joins us at the gravesite as we squeeze in together under the tent, trying to escape the blistering sun. The prayers, accompanied by a somber bagpiper, feel familiar from my childhood and evoke quiet sadness and reflection.

The rest of the burial though is filled with much more laughter than any of us expected. The releasing of the doves somehow goes terribly wrong; rather than all the doves being released into the sky in one beautiful move, they anxiously slip out of the basket one by one and hide away in a nearby tree. The newly minted dove trainer looks sheepish when he is scolded by the black-suited funeral director and apologizes endlessly. We shrug our shoulders and joke, "Grandpa and Uncle David are just playing tricks on her to welcome her into heaven." Even in our sadness, we can laugh and give grace to others.

Even more unexpectedly, the vault has not been installed into the ground. The funeral director seems very distraught by this and anxiously offers to have us come back in an hour or two when they are finished, but my family sees it as a chance to spend an extra hour with my grandmother before she's lowered into the ground. "We'll stay," we quietly decide together and settle into our chairs. Whether it's to keep a somber vigil with her one last time or make sure she doesn't come back to haunt us, half buried, is anyone's guess. The Irish are a superstitious people; we won't take any chances on an unfinished burial.

As we watch her grave being prepared, my uncles tell mischievous stories that would make my grandmother groan in her grave. They share with us out-of-towners their small act of rebellion. When my grandparents were planning their funerals years before, my grandfather wanted a bagpiper at his funeral, but when the time came to bury him, my grandmother refused since she thought it was tacky. Now that my uncles were planning her funeral, they decided to "forget" that little detail and hire the bagpiper anyways, just for a little lighthearted spite. "She's Irish...surely she wants the bagpiper but just didn't know it." So many irreverent jokes: something about the casket swinging open and her falling out. The rest of us shake our heads, pretending to be annoyed, but we laugh. "Tamp it down! Make sure she can't get out," one of them calls out to rings of laughter from the group.

Suddenly, I feel a flash of slight embarrassment, thinking of the strangeness of this entire moment and prepare to apologize quietly to my husband, so new to my family's antics. You can really only know the depths of how embarrassing your

family might be when there's a new observer. But then I notice his grin, his quiet banter, and his recognition that the family needs this relief amidst the sorrow. He's one of us now.

Over the next hour, we curiously watch the mystery of a burial stripped away. It seems so unholy to have a close-up view of the workers in their stiff gray uniforms, the heavy construction machinery, and the dump truck filled with dirt. All these are the parts families are typically sheltered from so they can focus on the emotions of grief. I think of the appalled look my grandmother would have on her face if she could see all this going on, but the rest of us seem to enjoy the way watching these pragmatic tasks gives a bit of a needed break from the heaviness of death. This seems appropriate; my family has always vacillated between facing emotion head-on and having tough conversations and shying away from things that seem too painful to talk about, whether it was about dementia or alcohol abuse or depression or dying or faith. Or maybe, because my grandfather was the epitome of an electrical engineer, we've all inherited a fascination with how anything and everything gets done.

As we watch the dirt layer over this deep hole in the ground where my grand-mother will stay after we leave and return home, my husband whispers to me, "How do you want to remember her?" It takes me longer than it should to answer with a simple shrug, but tears slide down my cheeks. Right now, I don't know how I want to remember her. All I can remember of her at this moment is an oxygen concentrator and labored breathing and weak muscles that kept her homebound and visiting my grandpa at a memory care unit before he died. But I know that if I

think deeply, there was a time that they were both healthy and fully alive: holding hands and squabbling and hugging grand-kids and walking through the alley to get to the hidden creek. I think of my grandpa tinkering with the garden in the backyard, smelling like wild garlic and onions, and my grandma sitting at the kitchen table chatting, one leg lazily crossed over the other. These are the memories that are both hard to summon and hard to forget.

The next day, I wake up to the sound of rowdy laughter in my grandmother's kitchen. I hear familiar voices and join them. "Want to come with us to the cemetery?" my uncle asks. "We're going to have donuts and chocolate milk and visit Grandma."

The next day, I wake up to the sound of rowdy laughter in my grandmother's kitchen. I hear familiar voices and join them. "Want to come with us to the cemetery?" my uncle asks. "We're going to have donuts and chocolate milk and visit Grandma." As if this were a totally normal thing, I say, "Sure!" and head back to invite my husband to join us. "We're going...where? To do what?" It was then that I realized this probably needs some explaining.

As many families do, my grandparents had a long-standing tradition of going to the cemetery to visit loved ones who had died. It was especially important to

them to visit loved ones who had died in World War I and World War II, not wanting their sacrifice to feel forgotten. Somewhere along the way, donuts and chocolate milk got added into the equation. No one really knows the exact origin of why: maybe remnants of an old Midwest ritual, maybe bribery for young children to go visit long-gone ancestors, maybe a nod to the banquet feast of the afterlife?

Now, 50 years later, this is still a way my family remembers those who have died and gives us a place to go relive all the tales that families love to tell. In all the years I've been making donut visits to the cemetery with the family, it's never been a very serious affair. There is usually laughter and storytelling and little bits of sadness and reality—they're gone, really gone, and all we can do is visit them here—scattered throughout, but not so much that an observer would probably notice them. You really have to look for the seriousness, but it's there, kind of like sprinkles on a donut.

Family-of-Origin: Things Aren't Always What They Seem Julia Sager¹

I am on a flight to Tucson, cruising at 36,000 feet above sea level, thinking to myself how extremely lucky I am that I don't succumb to flight sickness and usually am able to use plane flights to get a lot of work done. Not this time. My sister, who is across the aisle from me, sits up suddenly screaming, "He is poisoning me," and starts unbuckling her seatbelt. I fear that she is going to try to flee. After desperately not feeding into my own fears about what else I will uncover, I ask about her fears, unsuccessfully redirecting her. I guide us on breathing skills that we had practiced the day before, which proves to be unsuccessful. She starts escalating, "He has hidden cameras hooked up all around the house. They are connected to the locker room in the local gym, where they are all watching me." This is hour 5 of 9 of our travel. Thank God for the lovely flight attendant, who is more successful in redirecting my sister's emotions and focus. I am completely drained and realize that I will need to constantly engage my sister, for the rest of the day.

My goal is to stabilize and support her while we travel across country to one of the top inpatient rehabilitation programs for persons with comorbid mental health and substance use disorders. I will be dropping her off at midnight, where she will be involuntarily committed. This is number 5 of what will be 8 mental health hospital commitments for the year.

I flash back to my junior year in college, when I arrive home with my boyfriend for spring break on a Sunday evening, asking, "Where's Mom?" upon finding my father sitting alone watching television.

¹Published anonymously under a pen-name.