

Learning From Experiences of Chronic Illness: A Book Review of *The Room Sinatra Died In and Other Medically Adjacent Stories*

Reflecions by Ted Meyer and Commentary by Priyanka Bhakta, SPT

Summary

In *The Room Sinatra Died In and Other Medically Adjacent Stories*, author and artist Ted Meyer reflects on living with chronic illness. Incorporating both humor and introspection, Meyer weaves together various short stories to form a rich tapestry depicting the thoughts, struggles, and triumphs of living a life with Gaucher's disease—a genetic disorder that can lead to bone pain and the enlargement of one's internal organs. In this book review, Ted Meyers reflects on the process of developing this collection of stories and how the writing process itself impacted his own perspective on his life and chronic illness.

Author Reflections by Ted Meyer

I've never thought of myself as a writer. In college, I slept through my 8am English classes, barely managing to squeak through to graduation. A friend once evaluated my writing skills and concluded, “The

comma is not your friend.”

My prose has often been compared to William Shatner's acting—where, you, can, never, use, enough, commas.

Despite this unconventional approach and an undiagnosed case of dyslexia, I've always loved telling stories. I'm not 'creative' in the traditional sense—I don't write fantasy or romance. Instead, I focus on what's happening around me. I observe, reflect, and decide whether an experience might be unique to me. That becomes my starting point.

Growing up with an illness exposed me to situations most people never encounter—death, organ removal, and moments when people reveal both their best and worst selves. Writing about these experiences feels natural. They've shaped my perspective—and when I do write, those moments inevitably find their way into my stories.

The Room Sinatra Died In is a 15-year labor of love. I never imagined writing a book because I didn't see myself as a writer. The stories simply accumulated over time in a file I called Hospital Stories spread across a string of upgraded computers. The first was "Steven and Richard," in which I processed the simultaneous decline of my cat and my brother. At the time, I struggled to understand why my cat's deterioration felt so much more real and painful than my brother's decline.

Over the years, I returned to writing whenever I hit a creative block with my painting, but still needed an expressive outlet. Sometimes, in conversation with friends, I'd recall something that happened to me and think, "That's a good story." Writing is my way of preserving those moments.

When I ran into Nancy Reagan in Beverly Hills, I found unexpected commonality with someone I had long detested from afar. Because we had loved ones suffering through the same illness, I realized there might be a universality to these medically-focused experiences. That realization made me think they could work as a collection.

As the book came together, my partner Anna read the stories over and over, making suggestions on ways to fill things out. She saw the collection as a testament to how one person's illness touches an ecosystem of friends and family. She realized that my brother Doug—the 'healthy one'—needed to be represented in the book because my illness affected him deeply, too.

There are more stories in different states of completion sitting in that folder on my computer; hopefully, at some point, they will also see the printed page.

Commentary by Priyanka Bhakta, SPT

By sharing his unique life experiences, Ted Meyer inevitably tells stories that reflect the universal human condition related to both health and relationships. The stories convey the unavoidable impact of health on one's relationships and the people around them. The impact of illness on the family or community of the person affected, and the strong spirit of caregiving, for example, are reflected in these excerpts from one short story, "Karma":

"I've done the math. Between her mother Mindell, my dad, Richard and me, my mother spent over 75 percent of her life as a family caregiver..." (page 12)

"...I hope that if my mom is reincarnated, her next life will be easier. I imagine her as a fluffy purebred cat, living in a beautiful house on her beloved Connecticut coast, with no responsibilities. She would just catch the occasional mouse to let her owners know she was taking care of them." (pages 13-14)

These reflections highlight that the role of the caregiver can be incredibly time-consuming and physically/emotionally draining although it is often a labor of love and loyalty. Due to this dichotomy, the unique transformation of friendly or familial relationships into a relationship between one who provides aid/care and one who receives it can be difficult for all those involved in the rehabilitation process.

FAMILY-CENTERED CARE

For rehabilitation professionals, the ‘therapeutic alliance’ between patient and clinician is the primary relationship that is the focus of treatment and recovery. This alliance also relates to a commonly-taught method of treatment planning for rehabilitation professionals: patient-centered care, which necessitates providing treatment that is in alignment with the patient’s goals.

However, Meyer’s honest reflections on the impacts of caregiving (both positive and negative) challenge rehabilitation professionals to expand this alliance to address family/care team-centered goals. Broadening these therapeutic relationships will ensure that the needs of both patients and their caregivers are being considered and supported in the process of rehabilitation.

LANGUAGE AND EMOTIONS

Another impactful aspect of these stories is the way that the thoughts and sentiments Meyer shares provide insight into the feelings that many with chronic illness may have. For instance, in “I’ve Got a Disease or Somethin,’” Meyer recounts his father’s distaste for the term ‘disease’ and preference for ‘syndrome’:

“With illness, word choices do matter. Mutation, disease, syndrome, pile of crap. They project different things to different people. I’ve always felt pressured to describe my illness in ways that make other people feel at ease.” (page 60)

This excerpt highlights the impact of word choice, and of supporting rather than hindering one’s agency in discussing—and therefore experiencing—their illness. By emphasizing how language and actions can center on either disabled people versus nondisabled people,

Meyer calls on readers to challenge their own perspectives on language and perceptions of comfort when discussing illness/disability and when interacting with folks with disabilities.

ILLNESS AND HEALTH

In conversation about this new project, Meyer shared with me that when he believed he had finalized this collection of stories, his partner brought to his attention that he had written at least one piece focusing on each of his immediate family members *except* his oldest brother. His ‘healthy’ brother. Meyer realized that he had not consciously considered writing about his brother for his book about illness. He decided to speak to his brother’s wife to reflect on the possible impacts of his illness on his brother, which led him to write “The Healthy One.” Deeply personal, this short story—and the deeper story behind it—portrays the subtle ways that health and relationships are intertwined.

CONCLUSION

Ultimately, *The Room Sinatra Died In and Other Medically Adjacent Stories* is most powerful in that it provides insight into the lived experience of someone with a chronic illness. In a world that still marginalizes disabled voices and perspectives, this collection of short stories provides a safe space in a corner of our universe to listen and learn from the earnest voice of Ted Meyer.

The Room Sinatra Died In and Other Medically Adjacent Stories can be found at this link:

<https://www.amazon.com/Room-Sinatra-Died-Medically-Adjacent/dp/B0DFVD529D>.

Teaching Tools

Below are two stories from this collection that can serve as a jumping-off point for discussion of key themes from the book, which may be best suited for healthcare professionals/students.

“Karma” (pages 5-14)

This story is the opening short story of this collection, following the prologue, and is one of the lengthier stories in the book. “Karma” begins with a brief reflection on the concept of karma and quickly delves into an exploration of the life of Meyer’s mother. As the author recounts some of his childhood experiences being diagnosed with Gaucher’s disease and the subsequent waves of hospitalizations, he highlights his mother’s role in these experiences.

This piece provides readers a perspective on the complexity of being a care. It can serve as a discussion starter for healthcare professionals or students, prompting them to better understand the role that caregivers often play in rehabilitation as well as the impact that this role has on the caregivers and those for whom they care.

Discussion Points and Questions

- *The caregiver’s role in physical rehabilitation.*
 - Which of the various aspects of the caregiver’s experience highlighted in this story stood out to you most? Why?
 - Are there any aspects of the caregiver experience that you could address or support as a rehabilitation professional to improve the experience and outcomes for both your patient(s) and their caregivers?

How?

- *Expanding on patient-centered care to include caregivers/family.*
 - How would you describe patient-centered care and family-centered care? What are the similarities and differences?
 - Identify a sample case study (such as stroke) and describe examples of patient and family- or caregiver-centered goals and how you would address them in your intervention.
- *Caregiver support and resources.*
 - Do you know of any caregiver supports or resources to share with others in this discussion group?
 - Do you have ideas on how you or others in your profession/clinical environments can better prepare or offer caregiver support and resources?

“A Walk on the Pier” (pages 109-116)

This story is presented in the latter half of the book and takes place after Meyer moves to the San Diego, CA area following graduation from college in Phoenix, AZ. After his move, Meyer describes how he faced a severe exacerbation of symptoms of his Gaucher’s disease for the first time in many years. He describes the lack of social support he had in his new living environment, and his very gradual and graded improvements in pain and functional mobility. He recounts the profound difficulty of living through this period of heightened pain and impaired mobility without any social support.

He then details how he slowly increased his walking distance outside his apartment as his symptoms began to subside, with his end goal being the ability to walk to the end of the pier a few blocks from his apartment. The reader learns how he utilized benches on his way as stopping points/rest breaks and how he formed a brief but meaningful connection with his “bench compadre,” an older man with whom he often shared a bench when he made it halfway down the pier.

This piece puts into perspective what a lot of nondisabled folks take for granted in terms of functional mobility, prompting nondisabled readers to re-evaluate their understandings of pain, disabling events/exacerbations of chronic illness, and recovery from such events. This story can also prompt discussion of how individuals may independently try to rehabilitate themselves, the realistically slow and gradual process of rehabilitation/recovery, and the importance of sustaining/building community and social networks of support for recovery.

Discussion Points and Questions

- *Disability as a dynamic vs. static state/experience.*
 - Before reading this story, did you consider being disabled as a dynamic or static state/experience? Has your perspective changed after reading this story?
 - Can you personally relate to any aspect of the author’s physical or emotional experiences while dealing with and recovering from this exacerbation of his illness?
 - How does the concept of disability as a dynamic experience apply to the way that you think about disabled people in your life
- *Chronic illness and exacerbations.*
 - Are there any aspects of Meyer’s experiences during and recovering from this exacerbation of his illness that you can relate to personally?
 - Does the story’s description of a chronic illness exacerbation change how you understand chronic illness? How? Does it affect your perspective on how to work with individuals with chronic illness?
- *Self-rehabilitation, patient-centered care/goals.*
 - In this story, the author shares his thoughts and actions of working through his physical rehabilitation on his own. Have you ever heard about or personally experienced instances of folks who are ill or physically impaired taking on the challenge of recovering or rehabilitating on their own without professional help?
 - Are there any lessons about the rehabilitation/recovery process that you have learned from the perspective shared in this story, or from similar stories you might have heard before?
 - How does this concept of individuals working through their own rehabilitation process relate to the clinical practice of patient-centered care? How can you/we do better in this practice?

(including any relevant patients/clients) and/or the work you do as a rehabilitation professional?

- *Graded, paced treatment.*
 - Are there any aspects of Meyer's organically-developed personal rehabilitation process that mirror techniques utilized in clinical rehabilitation practice?
 - What are your thoughts on these treatment variables and their use/efficacy to various patient populations?
- *Impact of social support during rehabilitation.*
 - In this story, the author highlights how social support (such as the lack of support by his roommates in San Diego and the small uplifting support from his bench partner on the pier) can greatly affect one's experience with illness and recovery. What role do you think rehabilitation professionals play in contributing to the social support of the individuals they work with, to help maximize their progress during the rehabilitation process?
 - What actions can rehabilitation professionals take to help ensure patients are adequately supported socially during their recovery process?

About the Authors



Ted Meyer is an internationally recognized artist, curator and patient advocate who helps patients, students and medical professionals see the positive in the worst life can offer. Ted's decades long project "Scarred for Life: Mono- prints of Human Scars" chronicles the trauma and courage of people who have lived through accidents and health crises.

Ted seeks to improve patient/physician communications and speaks about living as an artist with illness. Telling stories about his own art and the stories behind his scar art collection, he offers insight into living with pain, illness, and disfigurement. Ted has been featured on NPR and in the New York Times, Washington Post, Chicago Tribune, and USA Today. His work has been displayed internationally in museums, hospitals, and galleries. As the Artist in Residence at USC Keck School of Medicine, Ted curates exhibitions of artwork by patients whose subject matter coincides with medical school curriculum. Ted has curated shows by artists challenged by MS, cancer, germ phobias, back pain, and other diseases. He is a Visiting Scholar at the National Museum of Health and Medicine, is a graduate of the Aspen Leadership Seminars, was the 2017 Sterling Visiting Professorship at Stanford University and has been a TEDx Anchorage and TEDMED mainstage speaker .

Ted's rare niche mixes art, medicine, and stories of healing and survival, drawing from his experience as a lifelong patient of Gaucher Disease (an enzyme deficiency that affects bones and joints). Ted spent much of his childhood in severe pain. His work is influenced by his many hospital stays where he began mixing art and medical supplies. (How can you make something out of I.V. tubes, bandages and pipe cleaners?) Contorted, graphic skeletal images appear in his early paintings reflecting his belief that he would not reach his 30th birthday. He now considers himself normal and healthy; outliving friends, family, and early expectations.

New drug treatments and joint replacements have improved Ted's life and this in turn has changed his artistic direction, shifting from "Ted-centric" images to those that highlight other people's health problems. His "Scarred for Life" series chronicles events that suddenly changed people's lives. During an expansive narrated visual presentation, audiences come to understand how a lifetime of chronic illness impacts an artist's work. Ted's curation turns devastating illnesses into a source of artistic expression, giving voice to people around the world living with rare diseases and disfigurement.

Ted's paintings have been shown around the world, from Europe, to Asia, and throughout the United States. With subject matter ranging from introspective, to

down-right humorous, his narrative always looks at human interactions.

Ted is a recent recipient of both a California Creative Core grant and CAC Individual Artist Fellowship, and the National Association of Practice's 2024 Patient Advocacy Award winner.

Ted is also a writer, photographer and illustrator. He has written and illustrated several books. "Shrink Yourself: The Complete do-it-Yourself Book of Freudian Psychoanalysis," "The Butt Hello - And Other Reasons *My Cats Drive Me Crazy*," "*Cats Around the World*," "*Good Things You Can Learn from A Bad Relationship*," and "*Scarred for Life*," His award-winning documentary, "*King of Dinoland*," follows outsider artist Abe DeLacerda. His new book, "The Room Sinatra Died In, and other medically adjacent Stories" to be released in September of 2024.



Priyanka Bhakta, SPT is a Doctor of Physical Therapy student in the Class of 2025 at Emory University in Atlanta, Georgia. She graduated with the Class of 2021 from UCLA with her Bachelor of Science in Physiological Science and a minor in Disability Studies. She is the current Senior Digital Graduate Editorial Associate for the Journal of Humanities in Rehabilitation. She is passionate about finding ways to integrate anti-ableism into physical therapy education and practice and hopes to integrate disability justice into the field of physical therapy and her future work as a clinician.