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The International Journal of Whole Person Care
Programs in Whole Person Care
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EDITORIAL

IN-BETWEEN WISDOM

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KEYWORDS: Uncertainty, Wisdom

One of my greatest challenges is to move forward in the face of uncertainty. As a kid I would play chess with my dad – outmatched by his skill, I would agonize over each move, desperately trying to avoid a mistake. Lately, I've been feeling like that chess-playing kid – wanting to move, *needing to move*, but frozen by not knowing which move to make.

When I settled on the theme for this issue, it was an entirely different season. It was summer and my swager was in full bloom. My focus for this editorial was on some far-off ideal. I wanted to hold something up to be celebrated – *See this! This is Wisdom!* – the embodiment of Solomon's virtue.

But then came fall and – *Poof!* – my confidence abandoned me. I was left searching for wisdom. Both in my own life and for this article.

And, now, I am left somewhere in between. I look out the window and large white flakes swirl lazily through the air. It's mid-January in Montreal and we've had two solid weeks of snow and cold. I've been teaching my daughter to ski over recent years and it's a bittersweet endeavour. Each trip a joy, but always left wondering about the sustainability of it all. Last year, the snow never really came, and I thought this would be our new normal. Nature is so full of grace.

As the articles for this issue stream in, I start to appreciate a theme – wisdom seems to live in these in-between spaces. There are evidence-based guidelines, institutional protocols, right from wrong. But wisdom isn't really needed to navigate the black and white. We need it most when facing uncertainty.

And, so, as the seasons change, my image of wisdom starts to evolve – from some objective ideal, to how I hold myself in these moments of doubt. Finding a way to stay rooted to something deeper than my current crisis.

I think this is what I lost in the fall. There's a sense of centredness that's been missing. This inner equanimity seems to be an important source of my wisdom. Without it, moving forward feels like stepping into the abyss. With it, I still don't *know* – but I can trust. It's this trust that allows me to tread more confidently into darkness.

During our last ski trip, my daughter got herself lodged into a powdery drift of snow. Normally a fall is followed by a flash of anger. But this time was different – with only her head and limbs sticking out, she sat frozen in startled awe before a broad smile slowly crept across her face – *like sitting in a cloud!*

I worry about what the future holds for my kids. How different their lives may be from mine. My hunch is that uncertainty will be on the rise. How can I prepare them to face the unknown? Celebrating simple, unexpected joys feels important. So does trusting that an inner sense of *good* may be enough.

The articles in this issue helped me cultivate a new understanding of wisdom and its various roots in my life. As you read through the issue, I invite you to reflect on your own sources of wisdom and how they might be nurtured into a foundation for venturing into the unknown.■

Biographical note

Timothy Wideman is a physical therapist and associate professor at McGill University. His research aims to help clinicians better understand and address suffering associated with pain, and to improve how future health professionals are trained to care for people living with pain. He has been serving as Editor-in-Chief since 2023.

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STORYLINES

LEADING IMPERFECTLY

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KEYWORDS: Perfectionism, Acceptance, Wisdom

My son is crying again. It's a weekday evening and he refuses to do his homework. In his frustration, he lies on the sofa, forearm over his eyes, shedding tears.

Lately, I don't recognize his behavior. I sit next to him and pause for a while before digging in.

"School is really, really hard." I say slowly. I wait for a reaction.

His eyes shielded by his arm, he nods his head.

And then, nothing. The nod was the most I was going to get.

"Sometimes rough things happen at recess." I try.

No perceivable reaction. I rack my brains for what else could be happening.

Then, unexpectedly, he blurts out: "I can't concentrate because I am so afraid of failing!" and he cries even harder.

I sit frozen on the edge of the sofa, utterly surprised. He has not failed at anything; in fact, he does well in most things he tries. How could failure have such a strong and dark grip on a thriving 7-year-old boy, I wonder.

Multifaceted

As though entering another dimension, I am sucked into my memories. Just a couple of years ago, my mother handed me some relics of grade school. Notebooks, pictures, etc. Among them was a card from my grade 2 teacher. I don't recall ever receiving the card, though I do remember the teacher. When I opened it, the message I read was the last thing I expected: "Sandra, do not be afraid of making mistakes." I was 7 years old.

*

When I was a resident, we used to receive performance evaluations at the end of each 4-week rotation. During one of these evaluations, a cardiologist had told me: "Be careful of the high expectations you have of yourself. Because when you have a family, your high expectations of them will drive them away." Both her knowingness and her concern for my wellbeing left a deep impression on me.

Since then, I have thought about her statement many times. The truth is, I am blind to my high expectations. I don't know when or how they show up, I don't know what language they speak or what their shadow looks like.

*

When my daughter was six years old, she fractured her arm. The morning after the ER visit, I was fussing about her, on that same sofa where my son lays crying. I was placing and replacing pillows, adjusting her blanket and the straw in her juice. She had looked up at me and said, without judgment: "Mama, it doesn't have to be perfect."

I had stopped in my tracks and stared at her. Where did her wisdom come from?
"Okay" I had agreed reluctantly.

The truth is, then as now, I have difficulty discerning where good-enough ends and where not-enough begins. Because there is a thread woven into my being called perfectionism.

My perfectionism thread shines and shimmers arrogantly and makes promises that cannot be kept. It utters threats of failure if I look away. And if I try to uproot it, it smiles smugly at my futile and destructive efforts.
As I sit on the sofa, I wonder if the same thread of perfectionism is woven into my son's being.

Kindness

The expressions of kindness that I have received over the years – care, concern and acceptance – have shown me that in the shadow of perfectionism, there is another thread. It is a humble thread called self-forgiveness. It is quiet, speaking only when spoken to. But when I place my faith in it, it sings a song so powerful that perfectionism is suspended. Failure is redefined as *intention* and *effort*; self-judgment becomes *acceptance* and *acknowledgment*.

I ask my son: "What will happen if you fail?"
"I will have to repeat my year."
"And what will happen then?"
He considers the question. "I will know all the answers already."
I feel relieved. For the moment, his fear of failure is dissolving.
"That's right, I say, and everyone will still love you. Me, your father, your sisters, your grandparents, your cousins and aunts and uncles and friends. Everyone will still love you, even if you fail."
My son seems to drop whatever he has been fighting with internally.
I realize that with tenderness, sometimes the blind *can* lead the blind, and the imperfect *do* guide the imperfect.■

Biographical note

Sandra Derghazarian is a community neurologist and a physician coach who has loved stories for as far back as she can remember. *Storylines* is a column in which she shares stories about work and life. As much as possible, she tries to stay loyal to the messy and sometimes contradictory experiences of everyday life.

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THE WISDOM TO NOT INTERVENE

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KEYWORDS: Whole person care, Healing, Wisdom in medicine

There are many definitions of wisdom. It is often considered the accumulated knowledge and experience of older people that can be passed on to the next generation. I was fortunate enough to have a wise, older physician as my mentor when I was a junior doctor, who shared his wisdom with me. He took me under his wing and taught me a great deal. His mentoring was largely by example; I learnt by observing him work with his patients.

One day, after we had finished an out-patient clinic (each seeing different patients, but discussing the consultations together), he looked at me and said "You know Paul, you are doing very well, but as you get older and more experienced you will stop prescribing so many drugs and realize that all you need to do is be there for your patients".

I did not quite know what he meant by that and, much as I respected him, I thought it a silly comment. We were practicing rheumatology at a time when new exciting drugs were becoming available which promised to provide patients with inflammatory forms of arthritis (our main 'clientele') a lot of relief. But my mentor was always saying enigmatic things to me about medical practice. For example, another of his aphorisms that stayed with me was “It is incredibly difficult for a doctor to do more good than harm, more than 50% of the time”.

I went on to pursue my own career in academic rheumatology. Early on, I undertook drug trials, and prescribed plenty of medicines, just like everyone else. But I never forgot those conversations that I had had with my mentor. And as time went on, I began to become disillusioned with some aspects of modern medicine, particularly the pharmaceutical industry. I realized that they liked to get us doctors to prescribe their drugs ‘at any cost’ – both figuratively and literally. It became clear to me that there was a lot of dishonesty in their promotional activity. Furthermore, all of their drugs caused frequent side effects, and many were downright dangerous. I stopped working with the industry and no longer accepted their largesse.

Then I had a ‘mid-life crisis’. An unusual form of mid-life crisis – I was taken hostage in Kuwait and Iraq for 5 months in 1990, as a result of being on a plane that refueled in Kuwait just as Iraq invaded the country.[1] I had many strange experiences whilst ‘away’, some of which awakened the spiritual side of my being (something that had been pushed aside by the ‘enculturation’ of scientific medicine).[2] When I emerged from the subsequent confusion and PTSD that followed my time as a hostage, I began to understand that the essence of good medicine lay in our caring for each other. Maybe that was what my mentor had been on about?

Through good fortune I was able to gradually change my research focus to placebo effects[3] and then to healing and healers.[4]

But I went on doing a little clinical rheumatology, consulting with small numbers of patients and trying to give them as much of my time as they needed.

Shortly before I finally retired from clinical practice, at the age of 70, I was doing an outpatient clinic in one of our local hospitals. I saw six different patients that afternoon. Afterwards, I reflected on my work, and realized that I had not prescribed a single drug, or indeed any other intervention, for any of those people. Nor had I ordered any investigations. I had listened, I had touched skin, I had laughed and cried with them, and I had offered some advice. The words of my mentor came back to me. Maybe he was right; and perhaps I had at last learned to simply ‘be there’ for my patients, and allow them to heal.

The wisdom to do less rather than more seems to be missing from most traditional Western medical clinical practices today. Indeed, we seem to be finding more things to investigate and more things to try to do all the time. We cannot let things be, or stand back and give nature a chance, as suggested by Victoria Sweet and the ‘Slow Medicine’ movement.[5]

So, what did my mentor mean by just ‘being there’ for my patients? He never explained it, but by observing the way he practiced medicine, I think he meant deep listening, great compassion, getting to understand their life and world, and perhaps love. The very first time I met him, when I was a medical student, he was doing a clinic. A lady with chronic rheumatoid arthritis came in and he immediately started talking to her about her family and her life at home. He really knew about her and her circumstances. He looked at her joints, felt them, all the time exchanging good-natured and amusing banter with her, and then reassured her that all was going well. Then he told her to ‘bugger off’ as she had had her time. She asked him when she could come again to which he responded there did not seem much point as he did not do anything or give her any medicines. “But doctor, you are my medicine”, she responded.

That consultation had a huge effect on me. Eventually it led to my learning to be the patients’ medicine, and not to rely too much on technology and drugs. I wish I had gained that wisdom earlier.■

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Biographical note

Paul Dieppe qualified as a doctor in London in 1970. He was appointed Professor of Rheumatology at Bristol University in 1987 and became Dean of the Faculty of Medicine there in 1995. He then worked for the Medical Research Council before moving to the University of Exeter in 2009 to pursue his interest in healing.

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HOLISTIC HEALERS OF ILLNESSES UNSEEN: PSYCHIATRY'S EMBODIMENT OF WHOLE PERSON CARE

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KEYWORDS: Psychiatry, Person-centred care, Mental health, Humanistic healthcare, Healthcare

"We'll be following up with you after we've had a chance to make a plan, ok? Alright, have a good day."
"Doctor, I've never had a good day."

The gravity with which these particular words were spoken lingered in my mind, uttered with a stoic conviction and without a hint of hyperbolic flair. Such a comment offered insight into a life marred by housing insecurity, psychiatric illness, and substance use disorder. On my consult liaison psychiatry rotation, I heard many patients describe suffering to an extent I could hardly fathom. I was struck by the degree to which my largely unremarkable, upper-middle class roots differed from my patients' circumstances. At this early stage in my training, I felt this disparity acutely, and worried that my patients did too. I experienced a creeping fear that despite my best efforts, patients might view such a glaring discrepancy as an impediment to the formation of a therapeutic relationship. I feared that in the eyes of those I sought to help, a conspicuous lack of shared lived experiences would render me incapable of understanding, and thus of truly helping. Would this fundamental divide stymie the rapport I was so desperately trying to build? Was I doomed to be regarded as a blathering white coat treating patients from the placid comfort of my ivory tower?

“We’re going to order some brain imaging and connect you with social work. I’m so sorry this has happened to you.”

“You’re a nice one, most people write me off. Thank you so much.”

Weeks later during an overnight shift in the emergency department (ED), I saw a patient suffering from psychosis who had been assaulted by her partner. Amidst the hectic scramble of the ED, I drew the curtain around us, offering a semblance of privacy. As I examined her for injuries, she told me her story. I patiently sifted through her recollection of events, which was frequently at odds with the triage notes and further muddied by tangential digressions. After explaining how we intended to help, it was her expression of gratitude (quoted above) that caught me by surprise. Worn-out and fighting exhaustion, I had not felt like I did or said anything particularly praise-worthy. As I reflected on the experience, I was reminded of my fears from several weeks prior. I had been so fixated on my perceived deficits that my struggle to connect with patients became a self-fulfilling prophecy. In this encounter, I leaned into the powerful simplicity of human connection. I had been putting undue pressure on myself to fulfill an unrealistically idealized role, one of an impeccably capable and infallibly empathetic clinician. This interaction taught me that patients are not asking us to be perfect; they are simply asking us to care. Psychiatric diagnoses emerge when biological and social factors converge and intertwine, permeating every realm of patients’ lives. Such exhaustive intrusion can potentially accentuate patient-provider dissimilitude. Empathy alone, itself a critical therapeutic modality, can help to span this gap, its importance arguably approaching that of pharmacologic intervention.

“I’m worried my interviews feel a little interrogative… I don’t want patients to feel bombarded.”

“The best psychiatric interviews will feel like a conversation to your patient.”

Herein lies the art of psychiatric practice, inextricably woven within the broader scientific fabric of pathophysiology and pharmacology. The more exposure I gained to psychiatry, the greater my appreciation grew for the nuanced impressions and conversational dexterity required to practice effectively. Haphazardly lobbing questions at patients, as I found myself doing as a fledgling medical student, proved to be a rather fruitless endeavour. This approach, a product of my limited clinical experience, reduced therapeutic encounters to the robotic completion of formulaic checklists. Though a sense of familiarity and comfort informed my choice to adhere to rigid templates, it flattened and homogenized patient interactions.

Frustrated with how these encounters played out, I solicited advice from my psychiatry preceptor. His above comment marked the beginning of a gradual maturation of my approach, which saw algorithmic interviews blossom into tactful conversations. Patients began speaking more openly with me, readily divulging intimate details of their lives. I appreciated the need to tailor my approach to suit patients’ individual needs and circumstances, cultivating a deep sense of personal and professional fulfillment in doing so.

“I appreciate your passion and dedication to your patients. Do you love what you do?”

“Every single day, every single patient, is uniquely interesting. Humans are amazing.”

Psychiatrists are armed modestly with only a pen, paper, prescription pad, and their words; medical minimalists who prefer to travel light. Whereas some physicians may be tempted to wade into the murky waters of biological reductionism, I have found that psychiatry is afflicted to a lesser degree. This could be a product of the underlying neuropathology, as an objective diagnostic test alone can rarely confirm a diagnosis. It could also result from the frequency with which a psychiatric condition infiltrates all aspects of the patient’s life, necessitating a holistic approach. As my preceptor’s comment (above) suggests, I tend to believe that this resistance against reductionism is born of a genuine fascination with the human experience. Psychiatry has long been the steward of a simple truth too often neglected in medicine: artful communication fosters true connection with patients. This is not scorned as an inconvenience, nor is it perceived to distract from the medicine; it is the medicine itself. As the painter applies their brush or the author their pen, psychiatrists leverage their communicative savvy to extract vivid depictions of the human experience. I am in awe of this ability, a marvel that serves to inspire me as I embark to train, with humble appreciation and reverence, for such an extraordinarily rewarding career.■

Biographical note

Alexandre Veilleux (he/him/his) is a medical student in the Class of 2025 at McMaster University in Hamilton, Ontario. He previously completed his Bachelor of Health Sciences with an Honours Specialization in Rehabilitation Sciences at Western University. Alexandre's keen interest in narrative medicine & whole person care has informed his decision to pursue residency training in psychiatry. He is also a former college football player-turned-coach, an avid writer, and an amateur naturalist.

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BALANCING SCIENCE AND INTUITION: THE ART OF CRITICAL CARE

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KEYWORDS: ICU, Medical Ethics, Medical decision-making, Health outcomes, Inter-professional communication, Lebanon

“Medicine is a science of uncertainty and an art of probability.” William Osler

The winter storm rages outside the hospital windows, typical of Lebanon’s winters. Rain lashes against glass panes while the wind howls through the streets. Despite being trapped for an hour in heavy traffic, I arrive at the ICU with unexpected energy running through my veins, my optimism standing in defiant contrast to the gloomy weather, eager to begin my morning rounds.

A chilling sensation suddenly freezes me, as if the storm’s icy fingers had reached through the hospital walls to grip my spine. Slowly, I turn, only to meet a piercing gaze that cuts through me like winter frost, its intensity challenging my presence in this ICU – a locale that is usually my comfort zone.

Through the observation glass of the Unit 6 corridor, our eyes meet. She stands there, her gray hair escaping from her cap, looking both strong and fragile at the same time. Her hands hold the metal rail tightly, as if she is anchoring herself to this moment, to this place where her child lies dying. In that single shared glance, I witness the entire universe of motherhood: infinite love and boundless fear.

Behind my mask, my lips barely release a whisper to the nurse asking about the patient admitted to the ICU just thirty minutes ago – transferred from the oncology department. The nurse's eyes soften above her own mask as she begins to tell me about Alain, who is just twenty-two years old. Her voice catches slightly as she explains his battle with lymphoma – how hope had bloomed during remission. Unfortunately, the cancer returned. Now, science and medicine stand powerless: no more options, no more possibilities. Alain urgently needs platelets, but every compatible donor, following the elimination protocol, has been rejected.

The silence that follows the nurse’s words fills the corridor with the kind of heaviness that only hospitals know. My mind takes me back, twenty-five years ago, to another young man, another mother. Same story. The cancer came back. He needed platelets, but we couldn't find any that would work. "I just wish... I just wish you could have kept him with us a little longer. Just a few more days to touch his hand, to smell his hair, to be his mother for just a little while more," his mother told me, her voice heavy with emotion, after I announced his passing.

In my early years of clinical practice, I was proud of my clinical knowledge. Textbooks and the latest research were my gospel. And I admit that I was not fully aware of the importance of listening and communicating with empathy and compassion with patients and their families during difficult moments like this. I should have expressed more understanding in that heartbreaking situation, rather than relying solely on the protocols. This experience has stayed with me.

I stand at the foot of Alain’s bed. My eyes move methodically from his smiling face to the monitors surrounding him and to his latest lab results. His respiration is rapid, and his heart is racing. He is bleeding from his nose. I can also simultaneously feel the echo of his mother’s love.

I leave the room and isolate myself in my office. I need to step back and reassess the case, to be able to take a different approach. Alain is dying; he will die anyway. If he doesn’t receive platelets, he will die within hours; if he receives platelets, he could survive for a few days. It’s no longer about cancer recurrence, medical expertise, protocols, and clinical evidence. It’s about Alain’s mother, father, and his two sisters. In the back of my mind, I am hearing “I just wish you could have kept him with us a little longer”, like to tell me: “Trust your instinct, protocols are just guidelines.”

I take a deep breath confident of my decision, ready for whatever challenges lie ahead, knowing that today, like every day in critical care, would bring new lessons and opportunities for growth.

Reflecting on the importance of communication in conflict situations with colleagues, I head toward the blood bank. There, in the waiting room, Alain's friends and cousins – young men and women from his university – are all eager to help and willing to donate their blood; some are already being turned away by the blood bank's physician.

Suddenly, my eyes meet the emotional eyes of Alain's girlfriend. It is her turn to answer the questionnaire. For a second, I imagine myself pulling her aside: "When you answer the blood bank's questions…perhaps you could...focus on relevant information only…omit something…a small lie…" But I immediately get rid of this thought. In my thirty years of practice and decades of medical ethics, I had never suggested anything like this before. After all, didn't these years teach me a lot about the power of communication?

Dr. Maria, the young blood bank physician, was doing her job exactly as she should. Each donor interview revealed something that triggered an exclusion protocol: recent travel, recent dental work, unclear medical history. The protocols exist for good reasons – to protect the blood supply, to ensure safety, to prevent disease transmission. But right now, these same protocols were becoming an immediate death sentence.

The next twenty minutes were some of the longest of my career. Finally, I am here with a humble smile, waiting for the precious units to be prepared. Alain stayed alive for seven more days.

This morning, the sun is rising as I drive to the hospital. Somewhere in the city, Alain's family is grieving. Despite her pain, Alain's mother has expressed her gratitude and respect for the whole ICU team.

Today, I feel more than ever the weight of thirty years in my career as a critical care physician. I find myself reflecting on the journey that has brought me here, to the kind of doctor I have become. Like Dr. Maria, I was once a proud young physician, swearing by the textbooks, following the protocols to the letter, yet sometimes the patient's condition worsened. With experience and maturity – both at work and in life – I gained the ability to see options in chaos, to know when to act aggressively and when to wait, when to trust the numbers and when to trust my instincts.

Wisdom! It is not about breaking the rules; the protocols exist for a reason. They are built on years of experience, on tragic lessons learned, on scientific evidence. They are designed to protect not just one patient but the entire system of care. But sometimes, in the balance between rigid adherence and preserving someone’s life, wisdom demands flexibility: it is about careful judgment in the face of impossible choices, careful deviation based on decades of clinical experience and an aware understanding of both the risks and benefits involved.

As I adjust another patient’s medication, I reflect on another aspect of wisdom I have gained over the years– the importance of clear, compassionate communication with patients and their families, but also its power to resolve conflicts with my colleagues. Wisdom also means knowing my own limits. Critical care is unpredictable, and wisdom lays in remaining vigilant, adaptable, and humble in the face of the body's complexity. Early in my career, I tried to solve every problem on my own. With time, I understood the strength of collaboration, in knowing when to call for others' expertise.

It's break time and I am enjoying my coffee. Nurses remember the days spent with Alain and his mother, the challenges, the ups and downs, but also the smiles and laughter when Alain's mother recalled his childhood years and silly things. Maybe the most important wisdom I have gained through the years is the ability to balance emotional engagement with professional detachment: to care deeply for each patient, to fight tirelessly for their lives, yet to find the strength to move forward when, despite every effort, a life was lost.

As I finally left the hospital that evening, I planned to work to establish emergency protocols for situations like this, where the rigidity of protocols and rules might conflict with immediate life-saving care. Because perhaps that's also part of clinical wisdom – not just making difficult decisions in the moment, but also working to improve the system so that future clinicians might face fewer difficult decisions of their own.■

Biographical note

Dr. Zeina Moukarzel is a retired anesthesiologist/intensivist from Beirut, Lebanon, with over 25 years of experience in intensive care, burn units, and anesthesiology. She holds a Master of Public Health (MPH) and a Master in Healthcare and Hospital Management, along with a diploma in addiction medicine. Additionally, she has an extensive experience in Lebanese hospitals accreditation. She is currently a university lecturer, teaching medical students a course on quality in healthcare.

Over the past decade, Dr. Moukarzel has dedicated herself to volunteer work, channeling her passion for healthcare into community service. In 2014, she founded LAMSA, a nonprofit organization focused on raising awareness about the dangers of tobacco, alcohol, and other psychoactive substances while promoting youth well-being.

A strong advocate for health promotion, Dr. Moukarzel is passionate about narrative medicine, mindfulness, and lifestyle medicine, highlighting the importance of holistic, preventive approaches to healthcare.

Writing Medical and Patient Stories - Dr. Zeina Moukarzel

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WISDOM IN HEALTHCARE: FINDING WISDOM IN UNEXPECTED PLACES

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KEYWORDS: Family medicine, Wisdom in healthcare

"Thank you for listening, for caring. Thank you for your advice, you are wise beyond your years," she said as the tears streamed down her face. The room was hot and heavy with raw emotion, swirling like dust in the rays of the mid-afternoon sun. "I will see you back here next month," I said thoughtfully as she stood up, collected herself and stepped out of my office.

Me… wise? Like many medical trainees, imposter syndrome followed me around like my shadow. Self-doubt caused me to question almost every diagnosis and treatment decision for most of my medical training. The evaluations from my attendings continued to feed the beast of self-doubt. I felt overwhelmed by the array of possibilities and investigatory options for any given complaint in a patient. How do I know the right course of action to choose? I have since learned that there is not only one right way to manage a patient.

Ask a group of five attending physicians questions about how to manage a case and you will have five different answers. I was so worried about selecting the "right answer"—as though life were some sort of multiple-choice question—that I was never able to select MY answer. I was only able to develop that independence after I had finished residency and was thrown into solo practice. Once I no longer had to prove myself to others, I felt liberated to trust my own assessments and come to my own conclusions. This liberation led to several wonderful developments.

I found myself moving away from simply giving my patients a diagnosis and a list of treatment options, and instead sharing my thought process with them. By explaining the nuances that made me hesitate between two treatments, I could work together with my patients to take the course of action that felt the most right for both of us. This strengthened the therapeutic relationship and, from my anecdotal experience, led to better treatment adherence.

In addition, it allowed me to explore the context in which I practice. Suddenly I saw guidelines not as absolute truths but suggestions to be tailored and individualized to each patient. Take Mrs. X for example; a charming older woman who has no underlying conditions to qualify her as immunocompromised apart from her age, yet she was hospitalized three times in the last year for a severe pneumonia. While she does not have asthma and has never smoked, she struggles with the grief of her husband’s passing two years ago. She worries about her daughter with breast cancer and often tries to help by taking care of the grandchildren. She never got sick like this before her husband’s death, and she has always failed first line antibiotics whenever I have prescribed them. So, when Mrs. X comes to my office with a deep, wet cough and the familiar chest pain, we throw away the guidelines and go straight to second line antibiotics because, for whatever reason, this is what works for her. This is her guideline that we created together through shared experience.

Finally, I started to innovate and get creative with how I practised medicine, something I previously thought to be forbidden. For example, I remember seeing an older woman with occipital neuralgia. The shooting headaches robbed her of time with family and knitting hats with her friends. When I discussed the usual treatment of occipital nerve blocks, she said she was deathly afraid of needles and asked if there was anything else we could try. I thought about it for several moments and suggested a trial of topical Xylocaine cream. I found nothing about it in my quick literature search at the time, but biologically it sounded plausible. I explained my reasoning and that I had no idea if it would work, but that given the low risk of danger to the patient, I figured it was worth a shot. Low and behold, it worked! She had relief and stopped needing it after two or three applications. A few weeks later I had another patient come to me for the same issue, except this time I did not have the necessary materials to complete an occipital nerve block. I proposed the cream with the same disclaimer, and she too wanted to try it. And once again, it worked. She came back to me several months later saying how empowering it was to manage her condition when it arose without having to go to the doctor for an injection. As she is a caregiver, leaving her mother alone was next to impossible. Something as simple as a cream made a profound difference in this woman’s life.

You can gather all the knowledge in the world and never be wise. Wisdom is not simply a collection of guidelines and facts; it is not memorizing diagnoses and algorithms. It comes from practice; from failure and subsequent growth, and most importantly from trusting yourself. Immerse yourself in the trials and tribulations of this amazing career and allow yourself to create your own guidelines. One diagnosis at a time, one treatment at a time, one patient at a time. ■

Biographical note

Dr. Laura Sang is a family physician with a passion for writing and health advocacy, currently practising in the lower Laurentians. She completed her medical training and a Master of Science in Public Health at McGill University. Additionally, she dabbles in freelance medical journalism. Her TV, radio, and print news appearances can be found on CBC and other news outlets. Outside of medicine, she can be found hiking in the woods with her husband and dog or curled up inside with a hot cup of tea.

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PINE TREES, TROLLS AND GOLDEN WINDOWS: A TALE OF TWO GRANDFATHERS

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KEYWORDS: Geriatrics, Aging

I grew up close to my two grandfathers, who were both Northern European men who found themselves in North America after the second world war. My Norwegian grandfather, known to me as Grampio, was an engineer and a storyteller. My German grandfather, who we called Opa, was a philosopher and a biologist. I heard little about their lives before coming to North America when I was growing up. Their pasts undoubtedly left indelible marks, but their presence while they were with family was very much in the present moment. Though they observed and made sense of the world through their own approaches, they were both men with tremendous curiosity about life and about other people. I was very lucky to have three decades with both of my grandfathers, and with reflection, I can see that my path toward geriatric medicine was influenced by their presence in my life.

Opa, a biologist, taught me about hypotheses and observation. He taught me to appreciate and notice the more minute details in the natural world - such as how to tell white pine (bundles of 5 needles) from red pine (bundles of 2 needles). I remember driving with Opa during an October afternoon, and listening to him listing all the signs of autumn – the colour of the leaves, the changing of the light, and the lengthening of the shadows. These signals from the natural world told a story, if we paid attention. Opa was grounded and contemplative. He thought and wrote about our connection with nature. His approach with people was considerate, and deeply respectful. He was also the first person to suggest I consider geriatric medicine. He would frequently meet with a colleague who shared a nearby office and learned through their conversations that they were married to a geriatrician. I remember Opa remarking, “I think Geriatrics sounds like it could be very interesting, actually.” He was correct.

Grampio was a mechanical engineer, and through his engineer’s lens, would solve and understand any and all problems at hand. When I was learning about liver disease, he drew a schematic for me capturing changes in flow, resistance, and pressure, to illustrate the concept of cirrhosis and portal hypertension. It was an engineer’s interpretation of physiology. Humor, sometimes very silly, and wonder shaped our relationship. He told stories endlessly, and I would listen as he would teach me how to tell a troll (vertical pupils) from an elf (tails are the tell). My favourite story though, was a fable he would share about the girl and the golden windows.[1] There once was a young girl, who woke up every morning and looked across the bay from her house to the town on the other side. All the windows in every house across the bay were golden, and she longed to touch them and enviously wished for golden windows of her own. One morning, she decided that she needed to see the golden windows, so she set out walking along the road through the woods to the town. The walk took her all day, and finally, she arrived in the town late in the day. She searched all around but was shocked to discover the windows on all the buildings in the town were ordinary windows! There wasn’t a golden window to be seen. An old woman emerged out of one of the houses, and pointed to the girl’s house across the bay. From her new vantage point, she discovered shining golden windows on her own home, glittering in the setting sun.

I believe that my experiences with my grandfathers guided me to Geriatric medicine, and I’m not alone in that regard – interviews with some of Canada’s first geriatricians identified close relationships with grandparents as an influential factor in pursuing the discipline.[2] I would struggle to call myself wise (doing so feels inherently unwise), but I do think the choice to study geriatric medicine was one of the wiser decisions I’ve made. It was a choice influenced by the role my grandfathers had in my life. By listening to their stories, their philosophies, and their experiences, I was shaped into the person I am today, and that led me to choose a field suited to me, my skills, and my passions.

Geriatric medicine is largely governed by navigating complexity. Understanding each patient’s context is an inherent part of each assessment, part of determining what “matters most”.[3] I bring medical knowledge and experience to each assessment, but the alchemy of wisdom occurs when I can integrate this with the information gained from observing, and listening to our patients, who are the experts in their own lived experiences. My vantage point is always enhanced by integrating the viewpoint of my patients and their caregivers – ultimately, it seems to take at least two to best judge the colour of windows.■

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Biographical note

Maia von Maltzahn is a geriatrician and medical educator at Dalhousie University. Her goal as a geriatrician and physician educator is to inspire others to discover the joy and privilege in caring for older adults.

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REFLECTION'S BOUNTY

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KEYWORDS: Communication in healthcare, Personal reflection, Wisdom, Clinical encounter

Knowledge is proud that he has learned so much;
Wisdom is humble that he knows no more.

William Cowper

A number of years ago, a new primary care patient's visit transformed the way I think about doctoring and the pursuit of clinical excellence.

A retired attorney in his mid-seventies, my patient had come in for a get-acquainted appointment at the advice of a good friend who was also a patient of our practice. He sat down next to me and clung tightly to a large, white envelope which I had been conditioned to fear might contain a merciless ream of health records to review. Maybe because of the way he held it next to him like something precious, I offered an inquiry that was distinctly outside of my usual repertoire so early in an interview.

"Is that something you would like me to see?"

As it turned out, the envelope did not contain medical records. Rather, it was a collection of remembrances of his son who had recently died from advanced cancer. I looked over the contents carefully and expressed my sympathy, and then we went on with the visit. He has since told me that it was my display of true interest in these papers that earned his trust, and he has since become one of my most grateful patients. A few weeks later, I began drafting a reflective essay about our first encounter.[1]

Around the same time, I was also studying for my internal medicine board re-certification exam, devoting an hour or so every evening to filling in gaps of forgotten facts and reinforcing new knowledge gained since the last exam. Afterwards, a few days a week, I spent fifteen or twenty minutes thinking and writing about my patient.

When the board examination date arrived around six months later, my brain was stuffed with refreshed facts and updated treatment strategies. Studying involved a careful review of prevention and treatment of disease. I reacquainted myself with things that were familiar, occasionally feeling surprised by how much some clinical strategies had changed over the years. Getting through this gave me a nice sense of accomplishment and reassurance that I was "up to date".

In contrast, thinking and writing about my newest patient was revelatory. I considered how I was trained to extract a patient's history, and how different it felt to just receive information from him the way he preferred to share it. How much richness had I missed over the years while trying so hard to control the flow and content of my patient visits?

After completing my essay and a few subsequent efforts, it felt like I was able to notice things during clinical encounters more clearly. Doing less talking often led people to share more thorough and interesting stories, which struck me as both illuminating and paradoxical. I began to enjoy taking note of how using certain phrases and gestures would put patients more at ease, and certain types of questions and phrasing brought out the most diagnostically revealing responses. It was as if, after years working in a room with lights dimmed, I had finally found a switch to adjust the brightness.

Whereas exam preparation gave me renewed knowledge, reflective writing improved how I applied it by helping to synthesize something complementary but altogether different: wisdom. And here is the most wondrous part – like a robust plant that keeps bearing fruit with proper nurturing, ongoing reflection has kept wisdom growing unrestrained.

There are innumerable medical facts to know – more than anyone can master. Electronic databases and artificial intelligence chat bots can supplement cognitive limitations here. Wisdom though, is entirely human, only constrained by experience accrued with mindful attention. Uncultivated experience alone, I have learned, does not automatically confer expertise. Wisdom, which combines knowledge and ethical judgement acquired through self-examination, along with consideration of many perspectives, is the true road to mastery.

Reflection, whether written, conversational, or in private thoughts, has become a standard part of my clinical life, and I think of it as similar to a regular workout routine. It is energizing, inspiring, and has made me a wiser, more fulfilled, and healthier doctor. I only wish it did not take me until mid-career to come to this understanding. But, as with physical exercise, better late than never. ■

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Biographical note

Jeffrey Millstein is a primary care physician, writer, educator, and serves as a Regional Medical Director for Penn Primary and Specialty Care. He is a Clinical Assistant Professor of Medicine at the Perelman School of Medicine at the University of Pennsylvania.

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THREE PATIENTS, TWO APPROACHES TO ILLNESS, AND A QUESTION: THE DNA OF CLINICAL WISDOM

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KEYWORDS: Medical error, Quality improvement, Reflection

There seem to be as many definitions of wisdom as there are examples—from the religious, to the linguistic, to the scientific and academic. In semiotics, the study of signs and their meaning, Baskara and Korionos[1] propose a hierarchy in which wisdom sits atop a pyramid of data, information and knowledge, each layer analyzed, ordered and incorporated into the next. From a clinical perspective (mine at least), the construct of clinical wisdom is recognizable but ill-defined, a cloth woven from the threads of experience, metacognition and perspective. The construct comes alive in its examples. I offer here observations from my own decades-long clinical and educational career, using a vehicle containing three patient stories, two reflections on the care of the whole person, and a question.

Let's start with the patients. After all, who are we without them?

Brad was in his late twenties when I first met him, early into my small, suburban family practice. Recently married with a newborn child and a brand-new home, he complained of lost interest in his job, his hobbies (he was an avid golfer) and, most sadly, his family. A tiny, overconfident psychotherapist lived inside me in those days, suppressed by a medical teaching system that favored the biomedical over the psychosocial. I pounced on an obvious diagnosis: “Reactive depression”, the little therapist said, blinkering me to other possibilities. After all, he’d undergone several stressful life changes in a little over a year. I suggested counselling, and, after a couple of sessions in which talk therapy was ineffective, an antidepressant. Six weeks later, the tricyclic (some readers may remember their unhelpful side effect profile) failed to work; if anything, his depression had deepened. Though not suicidal, he was clearly in need of more than my early-career skills. On his way out the door at our last session, he mentioned casually, “Jesus, doctor, I keep meaning to tell you: I am *so* constipated!”

I can’t tell you how often that doorknob elicited an important revelation.

“The antidepressants can do that,” I offered, but his answer set me back: “Oh no doctor, this was weeks before I started on them.”

The penny dropped, along with my heart.

My inner psychotherapist had blinkered me: I’d forgotten or ignored the evidence that GI cancers and depression are cousins. Frequently enough, they present together. A barium enema confirmed my fear. Brad had a particularly aggressive colorectal adenocarcinoma with metastases. The weeks’-long delay in his diagnosis had given the malignancy a head start. To this day, I remember my heart pounding and my face flushing as I read the X-ray report – the stigmata of guilt, the beginning of a kind of clinical wisdom. Strangely, the feelings of guilt or culpability, my most enduring teachers, were never once mentioned in my undergraduate or postgrad training. Mistakes? Medical error? They were never discussed.

Within the year, we lost Brad, one week shy of his thirtieth birthday and a month before the birth of his second child. Gone with him? The overconfident, psychotherapeutically-focused general practitioner. I re-doubled my focus on the biomedical. I became interested in teaching as a way to upgrade my own skills. I studied and became certified in family medicine, a relatively new training option at the time.

And then I met Deborah.

It was a few years after Brad's death; spring, the local river flooding its banks. Deb was in her fifties when I discharged her from hospital, recovering from an abdominal hysterectomy, the solution to fibroids and intermittent menorrhagia. She pointed to an area where the incision had broken down. I organized homecare and topical management for the minor infection, reassured her and signed her discharge.

Deb may have had a relatively uncomplicated hysterectomy, but she'd had a complicated year—her husband of two-plus decades had announced an extramarital affair, moved out of the house temporarily, and was now back home. The couple was in therapy. I'd like to think that I asked, "How are things at home, Deb?" but I am unsure. I'd like to think I got an upbeat response—perhaps, "Things are great, doctor. We're communicating much better, and I think we're back on track!"—but the years and my memory blur the conversation. What do I remember clearly? How much her hand shook as she pointed to the tiny infection in her surgical wound. How she couldn't look me in the eye. How, in the midst of a busy practice, I didn't explore the question, or even think, of the risk of self-harm.

Within hours, she was dead.

In a call from the emergency department later that afternoon, I learned she took a cab home and asked the driver to drop her at a bridge overlooking the swollen river. She could walk home from there, she told him. Horrified, the cabby reported what he saw in his rear-view mirror as he drove away: she ran to the low bridge railing, climbed over and jumped. He tried to save her, but failed, succeeding only in triggering an emergency response and a frantic, failing attempt to drag her from the river and resuscitate her.

What had I missed? The shaking hand when she pointed out the infection? The tell of her not making eye contact? I cannot imagine a pain that could push her to end her life. I can still unearth mine and observe it, a tiny sliver of hers, years later. Pain, a cousin of guilt, is also a gifted teacher.

And then, decades later still, when I had become a professor of family medicine, a kind of docent to other learners much younger than I, came a third wisdom-builder.

Meet Roger.

He was in his late seventies, most recently a high-end executive, now retired. Handsome, well-dressed (even in retirement he wore ties, each one costing more than an upscale dinner). Used to being in charge of things, he was bored. On the advice of his pastor, he decided to volunteer in a homeless men's program, and was registering drop-ins when one of the clients grabbed Roger's wrist. "Stop writing my name down! You can't record me being here!" the man shouted at my patient. "The FBI will know!"

Roger did as he was told, and the man loosened his grip on my patient's wrist. The pain persisted however, burning and deep, sleep-robbing. Later that week, I examined him but could find nothing serious—no bruising, no restriction of motion; at most, only moderate tenderness. My biomedical antennae were vibrating as I was reviewing the case with a medical student: was this a scaphoid fracture in an older man, at risk for osteoporosis? Tendinitis, myofascial strain? An arthritic flare? A week later however, after the X-ray and tests revealed nothing and the pain appeared to worsen, my student suggested an MRI. Now a wiser (and much older) family doctor, I offered a different approach. I pulled a chair closer to our patient and asked, "Does this pain remind you of anything, Roger?" I'd like to think it was the voice of my teachers, Brad and Deb, who inspired the question. "Remember us: we are whole patients", they might have said.

To our great surprise, the face of this particular patient, the handsome, in-control, well-dressed former executive, crumbled.

In tears, Roger revealed that his stepfather had molested him decades before, grabbing his wrist, forcing his pre-teen hand to the older man's genitals—and then demanding more. Later, his psychiatrist (thank God for caring and competent geriatric psychiatrists) and I were to learn how much more—details buried in his subsequent years of study, work and ambition. What followed was a layer-by-layer revelation of the anguish of child abuse, months of therapy and finally, thankfully, healing. The pain in Roger's wrist? It disappeared, never to return.

What thread holds the beads of these disparate stories, strung over decades, together?

If it wasn't clear before, the voices of patients confirm what we know about whole person care: we fail a patient if we only consider one side of the biomedical-psychosocial divide, an artificial separation if there ever was one. And this becomes clear too: if there is wisdom in clinical care, it's the consideration of these as one entity, not two, not unlike the strands of DNA that create us, doctors and patients, in the first place. At least from my perspective, their connectedness, interplay, and development describe the arc of a career, the evolution of clinical wisdom across a long clinical journey, milestones on a journey to a wiser—I cannot say wise—physician.

Wisdom requires more of us however: like the science of quality improvement, it also requires an insistent, unrelenting questioning. Quality improvement professionals ask the question, why? at each step in an investigation of medical error, repeatedly examining an issue and learning from it, a kind of forced metacognition. In the process, we must attend to those things that act as bridges between the patient and the clinician-learner—guilt and its cousin pain in my case, now more memory than feeling; truly listening to the voice of the patient; and the ability of the clinician to ingest and use the error messages.

Finally, it brings this question to mind, intended to probe the possibility that the journey to wisdom in medical practice may be shortened, that patients may be better aided in their journeys: is clinical wisdom teachable?

My patients and I would agree on one thing: we hope so. ■

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Biographical note

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PRINCESS OF THE NIGHT

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KEYWORDS: Wisdom, Person-centred care, Death and dying

"I'd like to see princess of the night."

New-onset confusion, probably a UTI. I glanced at the man sitting next to me, scrunched up in his wheelchair. He was fresh from the shower this morning, wrapped in towels and two gowns. His hands folded neatly on his lap. They were not pulling on his catheter.

"Maybe later, Norm." I smiled at him, switching his GCS assessment from a 15 down to a 14. Hopefully they'll start him on some macrobid. "I'll get you some pain meds and we can do your dressing in a bit."

He asked to see princess of the night again when I walked in to change his vac dressing. Another task on my to-do list for the day. Beth pulled out her third IV of the day, Steve started on a heparin drip, at least Ron is sleeping now — he was trying to throw a bedpan at me two hours ago.

Please don't be aggressively confused, just be sweetly confused. I thought to myself as I peeled Norm's dressing back. At least I'll have 30 minutes of peace and quiet while I do this, away from all the chaos outside.

“Have you ever seen one?” He turned his head as I was cleansing the wound.

“The princess? I would say, The Little Mermaid is my favourite, what about you?” I opened another bottle of saline. This wound is getting deeper, might need to get plastics to look at it.

He chuckled, hands on the bedrail: “No, not the princess. Princess of the night, the flower.”
Right, he was a botanist. I moved my dressing tray closer.

Slowly it was coming back to me, I was the one who did his admission and asked about his life. He told me about his career, his wife who passed from cancer, and his daughter who moved to Asia. Was it Korea? Or China?

But I had seen so many of them, engineers, chemists, plumbers, teachers, freelance artists, married, single, divorced, cheating on their partner, five kids, no kids, deceased kids…they began to merge together into one. Their lives weigh on me as one, and fade as one. My Tuesday became the worst day of their lives, and they drew their last breath as I was standing in the grocery store, picking between two tomatoes. There was too much to do, always too much to do.

I was burning out as a nurse, and everyone could see it but me.

“...it blooms during the night, and wilts before dawn.”

“Just for one night?” I dropped another silver dressing into the sterile tray. A thud came from down the hall, followed by “Get the lift!” Sounds like another fall, please don’t let it be Beth.

“You can go see if they need help, I can wait.” I caught his eyes this time.

“I’m okay, they have enough hands out there.” Plus, I’m already sterile. I began to apply dressing on the bony parts of the wound.

He turned his face away from me. It was a sunny day, the first day of summer. He could see the ocean from his window.

But he'll never touch the ocean again or feel the whispers of the woods. An elective surgery turned into an infection, the wound dehisced, then it was washout, antibiotic beads, then washout again, vac and a JP drain. The senior nurses said that he'll never leave this hospital again.

"I would love to see one bloom someday. I don't think anyone grows them here in Canada, but in Asia they have a few buds. They are called *tan hua* in Chinese. My daughter saw one in Hong Kong. She said it was beautiful, so beautiful, yet so fragile. Everyone gathered around it and they held their breath as it bloomed. It was as if they breathed too heavily, the flower would wilt."

But he'll never see one.

People leave the hospital one way or another. One time, when I was drowning between patients, I sat on an empty bed to take a deep breath. Then it suddenly crossed my mind, the last patient who laid on this bed, did they leave the hospital with family? Or did they die?

People who work in healthcare are different, we hold people's lives in our hands and see them in their most vulnerable states. The four walls of the hospital have likely heard more prayers than many churches. So, we armour ourselves with knowledge, we must be intelligent, smart, clever, and wise. Only by doing so, can we look a crying family member in the eye, and truthfully say "we did everything we could."

But the brain can only retain so much, we remember the Kreb cycle, the coagulation cascade, the twelve cranial nerves and their functions. So, to make room, we sometimes forget that behind that bilat amputee with DMII, HTN, GERD, CKD, is a man who wants to see a flower bloom.

"Didn't you say that you'll be going to med school?" He adjusted his gown. The back of it was wet, was it from the shower this morning? Or was it sweat? But the air conditioner was running, so it couldn't be that hot.

Perhaps he was in pain, and I was too focused on the dressing to notice. After all, he never said anything.

"Yea, I start this August."

"Well, congratulations." He pushed his hair back as he smiled. For the first time, I noticed that he had been chewing on his nails. I also do that when I'm nervous. "You'll be a fine doctor."

I never saw him after that day. He went into septic shock on my days off, then passed away in the ICU.

The purpose of the flower, as botany would describe it, is to carry out sexual reproduction. Their beautiful appearances attract insects, which helps with pollination. Most flowers bloom in the spring and summer, when bees and butterflies are the most active.

So then, what is the purpose of princess of the night? To just bloom in one night and fade away at the crack of dawn. It takes too much energy to grow a flower only for it to wilt in such a short period of time. Its flashing beauty gathers many around in awe, for the fleeting time, and life's fragility.

Was it worth it?

I thought about Norm for a long time after that. I thought if heaven was where the dead go, then it must be filled with all these flowers, since they are so short lived. Then perhaps he would be surrounded by them.

But I don't believe in that, so I ruminate on how fragile life is. How we are like flowers, some are like roses, some are like peach blossoms, and some are like princess of the night. They spent the entirety of their lives doing something that others cannot understand, something unfruitful, something beautiful.

Those people shine the brightest, and the world would hold its breath when they bloom.

In Buddhism, the word wisdom nurtures not only the mind, but the spirit and heart as well. In the vast sea of knowledge that we swim in, it can be tempting to dive deeper with every second, greedily grasping towards every bit of light we can. We are so thirsty for knowledge, to feed our minds, that we forget to breathe, and look at the flowers on the shore.

And when the princess of the night blooms, it is the most mesmerising. ■

Biographical note

Kelly Zhang is a medical student at Dalhousie University. Prior to joining medicine, she worked as a registered nurse in British Columbia and Nova Scotia. In her spare times, Kelly enjoys reading and trying new recipes.

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WISDOM IN HEALTHCARE

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KEYWORDS: Oncology, Wisdom in healthcare, Transplant, Pediatric patient care, Childhood experiences

It was a slow Sunday morning. I was disinfecting used toys in the playroom: the castle from Frozen, a model airplane, a Star Wars Lego set, and an endless amount of plastic fruits and vegetables from the farmer's market stand. As unusual as it may seem, it somehow felt wrong to disinfect them. The children who played with these toys were cancer patients and would spend every minute of their day in that playroom if they could. Wiping away the traces of what segregated them as children from cancer patients felt like I was doing something I wasn't supposed to do. It wasn't my place to erase the evidence of the fleeting innocence that they possessed and that someone as young as 19 years old, like myself, would pay any price to get back. Nonetheless, it was a hospital — a children's hospital for that matter — and hospitals have protocols that must be maintained at any cost and disinfecting used toys happened to be part of the protocol.

I sat on the awkwardly small, hot pink princess chair and began wiping. A young mother came running into the playroom. Her expression was one that I would never forget. There was something about the plum-stained pillows under her tired eyes, softened by the infallibility of her smile, that was oddly comforting to me. She nervously asked me if I would mind watching her daughter for a few hours while she and her husband went out for lunch with their family who had come to visit. I was slightly taken aback by her hesitancy in asking me, as if there was a chance that I would refuse.

She walked me over to room 7 — her unsureness behind my commitment now made sense to me. The perimeter of the door was adorned with dozens of caution signs, pictograms, safety measures, and a singular sticker of a cartoon kitten at the center which desperately attempted to humanize it all. Room 7 was reserved for cancer patients who had undergone organ transplantation and anyone other than the patient's parents, nurses, or doctors were advised not to enter. I was a volunteer who came in every Sunday morning at the pediatric oncology unit, thereby implying that I definitely wasn't qualified to venture in.

Just as I was about to contritely inform the mother that I was forbidden from entering her room, she clenched my hand and frantically pleaded for me not to leave. It was her birthday and all she had wished for was to have lunch with her family and ensure that her daughter was taken care of. How could she possibly assume that I — who wasn't even deemed eligible by the hospital to step foot in her room — would be fit to watch over her child? Even though I sensed the guilt and uncertainty coursing through what felt like every vein in my body, knowing that I was bearing the trust of a mother somehow negated it all.

I received permission from the nurses and proceeded to conceal every inch of my body with layers of protective gear. I was practically unrecognizable and yet when I briefly glanced at my reflection in the glass window, I knew that this was exactly what I was meant to be doing.

I approached the crib in the center of the room — watching my steps and avoiding the wires that lined certain parts of the floor — and there lay the most precious two-year-old baby I had ever seen. She was delicate and was wearing a frilly pink dress. I was worried that she would be frightened by the state of my appearance given that I didn't look human at all, but she was unfazed by it. I realized she had probably seen more people encased in protective gear coming and going from her room than I ever had in my entire life. She had her father's nose and dark hair, but her mother's eyes and perfect smile shone through.

After giving it some thought, I was able to piece together from where this all bizarrely seemed familiar. I too was once a two-year-old who spent her days under supervision at the hospital and my mother was also once in the exact position of that same young mother with the tired eyes and the infallible smile. From what I was told growing up, my mother would similarly yearn for a moment of normalcy as she would spend her days restlessly praying for the health of her child. This may have been 17 years ago but some things – like a mother's willingness to sacrifice for her child at the expense of herself – never change. My mother never got a break but that didn't mean that she didn't deserve one.

I then felt a greater sense of responsibility over the baby girl who was a stranger to me just a few minutes ago. I watched over her as I dangled my hands — veiled by a pair of thick purple latex gloves — over her face while singing every nursery rhyme that had been locked away somewhere in my brain for far too long. There were moments when I found it hard to believe that this seemingly perfect, happy baby girl was both a transplant and cancer patient and wouldn't learn about it herself until years later, when her mother decides to tell her.

I still remember when my mother told me that I had spent most of my early childhood years in the hospital. I remember asking her to swear that she wasn't playing some sick prank on me — not that she was the type to ever think of doing something so unfathomable anyway. I remember everything making sense at that moment. Why I had to go on multiple yearly checkups when my friends would only have to go once. Why the doctor's office was always filled with specialists, medical students, trainees and never just a doctor. Why my family always closely watched what I was eating or how I was moving. It all made sense.

Hours have never felt so fleeting and her parents were already peering through the window. Her mother thanked me as I left, and my heart felt as if it was seconds away from jumping out of my chest. I felt as though by helping her, I had given back in some way to my own mother and that I had healed something in myself that I didn't realize needed healing.

The experience I had with the young mother and her daughter taught me that the patient isn't the only person who is affected in a medical context — they may be the ones who are physically bearing the illness but the consequences of their diagnosis spreads immediately to those who are closest to them.

The concept of wisdom is often closely associated with age and the diverse array of experiences that one gathers over the course of their life. In healthcare, wisdom is imperative to a physician's moral judgment and to their ability of making critical decisions. I will always remember this experience and will use the lessons that I have gained from it, along with those I will continue to gather, as I pursue my career in medicine. ■

Biographical note

Kamilia Shome is in her first year in the Undergraduate Biomedical Sciences Program at McGill University where she is majoring in Biochemistry. She strives to pursue a career in medicine after completing her undergraduate degree. Kamilia devotes most of her free time to volunteering at hospitals and is passionate about whole person care with a particular interest in oncology.

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WHEN DECEPTION PROMOTES DIGNITY: THE ETHICS OF USING ILLUSION TO CREATE SAFE SPACES FOR PERSONS LIVING WITH DEMENTIA

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ABSTRACT

Caring for persons living with dementia (PLWD) is challenging. Some of the most challenging aspects include managing behavioural and psychologic symptoms of dementia (BPSD). Many patients and families will consider dementia care facilities to better manage BPSD, which can contain design elements that use the physical environment to decrease BPSD by deceiving residents and controlling their behaviour—all for their own benefit and safety. This immersive approach to behaviour management represents a more holistic *way to manage BPSD. Considering the especially vulnerable status of PLWD, these design elements should be thoughtfully implemented, researched post-implementation, and discussed with patients and their loved ones. The design-based approach to managing BPSD demonstrates the obligation healthcare providers and facility designers have to be more holistic in designing care environments for PLWD, especially for those living in dementia care facilities.*

INTRODUCTION

At some point in life, most people will consider moving themselves or a loved one into an institutional care environment. For many, the reason will include a diagnosis of dementia, a progressive condition that increases in likelihood with age and impacts both cognitive function and essential activities of daily living (e.g.: bathing, toileting, eating, etc.). In addition, behavioural and psychological symptoms of dementia (BPSD) often cannot be readily managed at home (e.g.: agitation, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes, etc.).[1] Even in the institutional setting, managing these behaviours is both difficult and, some would say, undignified. To decrease agitation and minimize the subsequent use of restraints and/or psychotropic medications, memory care facilities over the past twenty to thirty years have turned to innovative behaviour management strategies, including strategies to control behaviour through the design of the physical environment. However, the concerns about dignity have not been solved, and these management strategies raise important ethical questions about deception, consent, and autonomy. The presence of dementia in this population further complicates the assessment of how best to resolve these questions.

BACKGROUND

Caring for persons living with dementia (PLWD) is challenging; some contend that those challenges may be managed more safely, and perhaps with more dignity, by using illusion and deception to control behavior than through traditional means of behavior management (i.e.: chemical and/or physical restraint). As a result, those considering institutional care environments for themselves or a family member with dementia are increasingly faced with novel choices about their living environment. Advances in medicine, architecture, and neuroscience have enabled the creation of physical environments intentionally designed to decrease BPSD by deceiving residents and controlling their behavior—all for their own benefit and safety.

The kind of immersive design techniques used to control behavior through environmental design matter. For example, a mural may be used to conceal a door to a medicine room thereby rendering it invisible to residents but not to the staff.[2] Concealment is not new: there can be good reasons to hide something that is unsafe and will invite conflict, particularly when one is responsible for the safety of others who cannot always make safe decisions for themselves. Another design-based intervention involves placing horizontal stripes on a floor before an exit doorway, which due to neurological changes and visual processing system changes seen with some types of dementia, can lead to the striped pattern being perceived as a barrier, perhaps as three-dimensional stairs, thus impeding the desire to exit a space.[3] Anecdotally, a black square in front of a door or an elevator can dissuade a person from approaching it, as the black square may be perceived as a hole in the floor.[4] These and other techniques are used to ‘steer’ PLWD away from areas that they perceive as unsafe or to promote safe wandering practices.

Some facilities utilize deeper and more immersive levels of illusion. Often PLWD will seek to ‘go home’ and become agitated if they are not allowed to leave or wander.[5] Some facilities utilize non-functional bus stops, where a resident can be taken to wait for a bus that never comes.[6] Due to short-term memory impairments, the resident eventually forgets what they were doing and can then be guided back to their room without feeling powerless or angry. Other facilities have shops with fake money that residents can use to buy real food.[7] Paths and walkways through the facility allow for “permissive wandering,” but there is no way out; residents are ultimately locked in.

DISCUSSION

The ability to avoid sedation and restraints to manage BPSD in PLWD has been a long-sought goal. However, how a laudable goal is achieved is important. While the precise mechanism by which these interventions function is not fully understood, and varying levels of evidence exist to support their use, there is a difference between concealing a door, so a resident overlooks it and inducing a fear response when the resident approaches something they perceive as unsafe.[8] A useful concept here is proportionality, which refers to the idea that avoiding one’s harm is not justified if doing so causes equal or greater harm, and by extension, an obligation to seek the least harmful means to achieve a goal. Just as with medical treatment, we should employ the least invasive or harmful means to achieve a given end.

This is not to say that design-based interventions are not appropriate. While it is deceptive to build an illusory environment that creates a false sense of freedom and autonomy, the alternative may be equally or more concerning. While dementia facilities have made great strides to move away from using medications and restraints to manage unsafe behavior, there are often few remaining options to de-escalate resident behaviors when non-pharmacologic interventions fail.[9]

The use of deception in medicine is subject to strict controls, both ethical and legal.[10] This oversight ensures patient's rights are observed, which generally means their autonomy and dignity are respected. Typical examples of nudging in medicine, for example, involve minor effects on a choice architecture that remains within the patient's control.[11] Placing a person in an immersive environment with broad and persisting deceptions from which they cannot exit presents a new dilemma in bioethics and for society at large. This is particularly concerning when we consider that most PLWD do not want to go to a long-term care facility to begin with, and once there, they frequently express their desire to go home.[12]

The goal of whole-person care promotes not just physical health, but emotional, social, and spiritual health. The choice of which to prioritize when not all can be achieved is a deeply personal one. The bioethical principle of Respect for Persons captures the idea that each person is an autonomous, unique, and free individual who has the right to make their own choices.[13] Some residents may prefer to bang on a locked door, knowing that it is locked, and remain aware that they are not being allowed to do what they seek to do. Others may prefer to be deceived if their anxiety and comfort are better maintained by doing so.

The implications of this in the care of PLWD are complicated by the lack of, or limited, medical decision-making capacity. To be legally respected, such decisions would have to be made before the onset of moderate or advanced dementia, which is not always possible because loss of capacity often occurs before functional impairments that necessitate assisted living. Thus, by the time a change in one's living situation is forced, the patient has often long since lost the level of capacity needed to evaluate the options and provide informed consent. Obtaining assent is one potential solution to this issue, but many PLWD express changing preferences. Assent at one point may not limit disruptive behaviors from emerging later based on the desire to go home but does little to relieve situations in which a patient insists on going home but cannot be managed there. There are few broad and straightforward approaches to determining how best to respect PLWD's expressed preferences, even when considering dementia-specific advance directives.[14]

In situations where a person cannot decide for themselves, there are two decision-making frameworks their surrogates may use: the Best Interests Standard and the Substituted Judgment Standard. The goal of the Best Interests Standard is to determine, as best as possible, what choice objectively maximizes the patient's interests, such as health, safety, comfort, and so on. The Substituted Judgment Standard is preferred because it asks what the person themselves—from their own subjective standpoint—would choose, were they able to do so.[15] However, the Substituted Judgment Standard is complicated even if the person's prior wishes are clear to their surrogates. In dementia care, Substituted Judgment has been framed as the "prior competent choice," but what someone thinks they want in the future may vary greatly from what they want when the future becomes their present.

Even if persons lack medical decision-making capacity, their ability to express a genuine, rational preference based on the impact of that living environment on their quality of life may remain intact. A person may consistently express a desire to go home, for example. While PLWD may lack a significant degree of autonomy, they often possess enough capacity to make at least some decisions for themselves at times. Utilizing or avoiding deceptive or illusory measures in this context can therefore be seen as a form of respect for these persons' preferences to live in a different environment.

While design-based interventions may offer a more ethically satisfying way of managing BPSD in PLWD, the current state of their implementation and effectiveness is largely unknown, calling into question any conclusions about their appropriateness. Many of these design techniques are currently implemented and utilized with insufficient or no research on efficacy or risks. By comparison, when medications, medical devices, or medical treatments demonstrate a similar ability to impact medical outcomes and behaviors, oversight is required. However, adequate oversight does not exist for built interventions to control the behavior of PLWD.[8] In a striking example, a recent proposal for a dementia care facility known to one of the authors, involved making every mirror in a facility digitally 'de-age' residents so they only saw a younger version of themselves, similar to the photographs in the award-winning photo series "Reflections of the Past" by photographer Thomas Hussey.[16] While this idea is based on a mirror's potential as a design-based intervention to make living spaces of PLWD more pleasant[17], it is an example of the new Wild West in long-term care: interventions are implemented without the consent of those most affected, without oversight into the decision-making process involved, and without research or follow-up to assess efficacy, risks, and benefits.

A whole-person care approach to managing BPSD in PLWD through facility design aims to enhance the physical, emotional, mental, and spiritual well-being and wholeness of each resident with dementia. While the physical expression of these values will differ with each implementation, we see three common aspects of including beneficence in facility design:

1. Design elements must enhance residents' quality of life. For example, designs that improve social connection and reduce isolation have the potential to decrease residents' morbidity and mortality.[18] PLWD, although often lacking in capacity, can still often express true and valid preferences about their quality of life worthy of respect.
2. Design elements must not influence behavior by generating a fear-based response or inducing other traumatic triggers. This would likely differ from patient to patient and could be confounded by the disease process of dementia itself but would entail eliminating design elements that appear to cause PLWD fear, distress, or agitation.

3. Design elements should aim to preserve functionally appropriate autonomy and control. Where physical harm would result, the principle of proportionality applies: the anticipated physical harm should outweigh the dignitary harm of taking the choice from the person. This reflects the principle of obtaining assent from residents unable to consent. It is respectful of one's human dignity to engage them in a discussion of any given treatment to convince them of the merits of the treatment path and gain their agreement, even if they are technically unable to legally consent. Even if one lacks ultimate control over their legal and practical affairs, this does not mean that they should be disbarred from the decision-making process.

CONCLUSION

Immersive design techniques that influence behavior to manage BPSD in PLWD have the potential to drastically improve on current management of BPSD. Utilizing the evidence above, immersive design techniques can offer a more dignified, less harmful way of managing the BPSD of PLWD, particularly for individuals who seek to practice a holistic approach to patient care. But to support their use and continued development, these design interventions must be thoughtfully implemented, researched post-implementation, and discussed with patients and their loved ones. A great deal of work remains to establish protections for these vulnerable members of our society. The obligation to be more intentional about our care for PLWD is an acute matter, especially for those living in institutional care environments. ■

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