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EDITORIAL

COMMUNITY SPIRIT

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KEYWORDS: Community; Connection

It is springtime in Montreal, and the park is absolutely packed. Leaning against a tree, I feel winter finally slip away as a light breeze and sunshine reach skin that has been hidden beneath layers for more than half a year. There's a magic in the air that makes new connections effortless – a joyful ease with others and one's surroundings that is ineffable, but feels like home. This feeling of renewal and belonging reminds me of the first time I attended a Whole Person Care congress, some seven years ago.

At the time, I was navigating the tenure application process – a tumultuous period in an academic career. This uncertainty drove me to sign up, on a whim, for the Congress. I did not know what to expect but was hoping to find something – anything – that might help make my post-tenure work more exciting and meaningful. I still remember the trepidation that I felt before joining the opening plenary of the Congress. *What am I doing here?* The question screamed through my head as the escalator slowly pushed me from my professional comfort zone, toward a wall-sized *ensō* poster.

But then Rana Awdish started her talk. She simultaneously spoke with the full confidence of a seasoned medical expert and the wounded vulnerability of a patient who – like too many others – had been traumatized by her experiences in the healthcare system.[1] She outlined a vision for how we, as a healthcare community, must move forward with more compassion, humanity, and, dare I say, love. It was like the fresh air of spring, the sunshine after the long winter. And it seemed to float me to the microphone as she wrapped up. I rarely speak at these types of gatherings, but found myself talking about the vague sense of longing that I had been experiencing and my gratitude for Rana's message, which seemed to point

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a precise finger at what I had been searching for. *Where did that come from?* This became a recurring theme throughout the weekend – connections with others that continued to inspire an unfiltered openness that felt both surprisingly novel and natural.

Since that congress, I've found a deep sense of community within Whole Person Care; a sense of place that is incredibly rare in my professional world. There is a groundedness. A sense of comfort and familiarity. A loss of self-consciousness. That ineffable, home-like feeling of springtime in a park.

I've learned over the years that, in many ways, this spirit of community is no accident. But, rather, our group has been blessed with gifted leaders who have thoughtfully fostered and nurtured this sense of place and belonging among so many. Balfour Mount pioneered palliative care and, together with Tom Hutchinson, developed McGill Programs in Whole Person Care. Their contributions have shaped a generation of health professionals and helped transform patient care. This journal would also not exist without their leadership.

Lately, however, our community has been in transition. Bal died last fall and Tom retired in December. Our group has also been navigating important funding cuts that have contracted our work to the bare essentials of our mandate in teaching and scholarship. My hope with this issue was to try to put a finger – perhaps, as Rana did for me – on what we've been missing and where we might go from here.

Bal and Tom

People loved Balfour Mount. He was a visionary and charismatic leader. I never met Bal, but I continue to feel his presence throughout the Whole Person Care community. Last fall, the McGill Palliative Care program that he founded (and that, decades later, cared for him at the end of life) hosted a touching memorial in his honour. The event was full of people who had been forever changed by Bal – a testament to his gifts in creating community. A small anecdote from one of his colleagues stands out. Bal had booked a meeting with a fellow organizer for the upcoming palliative care congress that they were planning. Just prior to the meeting, which was typically held in a hospital conference room, Bal insisted that they needed to relocate to his home. Upon arrival, the fellow organizer was ushered into his den and asked to sit on a couch and don a set of headphones. Bal then proceeded to play a track from Pink Floyd's *The Wall*. He had apparently been contemplating the perfect closing anthem to the upcoming congress and wanted a second opinion. A simple story, among many, that provides a window into Bal's effort and detail in crafting a desired atmosphere that might help open others to new insight and inspiration.

Tom has a similar gift. The numerous community-building events that he led were always a unique mix of science and art. He has a special way of breaking with convention to deepen relationships. I remember a meeting he organized to help introduce our leadership team to another group that had a complementary focus. We met in their hospital-based research centre and, just as we were settling in, Tom pulled out a

large bottle of whiskey and suggested that having this conversation over a drink might be just the thing to inspire new collaborations. He also has a unique capacity to use the arts to inspire a whole person approach to practice. For years he led a film series event that invited members of the public into reflection and discussion about whole person care. Similarly, at the recent launch of his memoir, *The Craft of Medicine* [2], his skills were on full display. The local independent bookstore (which had long been a supporter of our events) was filled to the brim. Tom started his address by reciting an intriguing poem, “Fire” by Judy Brown, which he deftly integrated throughout his address. The room was filled with a rich sense of fellowship – it was clear that everyone in attendance felt deep affection and gratitude for Tom, and for his many contributions.

Cultivating a Spirit of Community

The number of submissions that we received in response to this issue’s call was unprecedented – clearly, community means a great deal to people drawn to whole person care. This makes sense to me. In many ways, to practice whole person care is to work somewhere near the margins of mainstream health care culture. It involves holding onto values, forms of attention, and ways of being with patients that are not always easy to name, measure, or defend. It involves a belief that health care can be more human, more relational, more attentive to suffering, meaning, and personhood. But carrying this belief alone can be untenable. The pieces in this issue speak to this tension in different ways. Together, they remind me that community is not simply a pleasant complement to whole person care, but rather an essential piece of what sustains this work.

During this period of transition within our own Programs, I have been trying to better understand what goes into creating this kind of community. My sense is that, at its centre, there needs to be a feeling – a spirit, if you will – that inspires comfort, trust, joy, and openness with others. There are, of course, practical structures that give a community form – meetings, journals, seminars, budgets, leadership roles. Without these, community can quickly become too disjointed to sustain. But structure alone is not enough. As Judy Brown suggests, tending a flame requires attention not only to the wood itself, but also to the spaces between.

Bal and Tom seemed to understand this. Their gatherings had form, but also openness. They created containers, but left room for surprise. A song, a poem, a film, a shared drink – these were not ornamental details. They were small invitations to enter the work differently. They helped people lower their guard, notice one another, and become more available to the possibility of connection.

I am still learning how to do this. I am learning that community requires more than admiration for those who know how to create it. It asks something of all of us. It asks for time, attention, and effort. It asks for a

willingness to show up before we are certain of the outcome. It asks us to risk small gestures whose value may never be captured in a report, strategic plan, or annual review.

Moving forward, I hope to keep stepping onto escalators that carry me out of my comfort zone. I hope to keep trusting that not all essential outputs are tangible. And I hope to help create spaces where others can experience something like what I felt during that first Whole Person Care Congress – a sense of recognition, possibility, and belonging that I had not quite realized I was missing.

As you read this issue, I invite you to reflect on the communities that have sustained your own work. Where have you found a sense of belonging? What helped create it? And what small role might you play in helping to create that spirit for others? ■

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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

STRIVING

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KEYWORDS: Pilgrimage; Camino de Santiago; Spirituality; Community; Connection

Seventeen years ago, in the span of a moment and without any rational explanation, I decided: that spring, I would travel to the Camino. I would walk 20-25 km daily for 3 weeks, going from town to town in the North of Spain along an ancient pilgrimage route. I would sleep alongside a group of strangers in dedicated pilgrim hostels. My backpack would need to contain only essential belongings. And, like the majority of pilgrims, I would leave my phone behind. This was a great departure from the way I lived my life: future-oriented and comfortable enough. But by the time spring came around, I was ready and excited.

And with reason. Those 3 weeks of pilgrimage are etched into my mind and my being. Walking for long distances every day alongside other pilgrims allowed me to deepen my relationship with life in a way that I had not previously experienced. The Camino opened up a path for spirituality, connection and growth.

Awe

The spirituality inherent to the Camino rubbed a sacred reality into me: that of the infinite smallness of human beings and that of their immeasurable worth and wholeness. Up to that point, I had not thought those two truths could co-exist or even less, be integrated. But, through different encounters, the Camino taught me to hold those two truths simultaneously.

One such encounter occurred on a grey morning when I was walking alone. As was expected from the weather, in the mid-morning it started to rain. As I pulled my poncho over myself, it ripped at the shoulder seam. Rain fell unhindered onto my backpack. I felt indignation rise in me at the anticipation of my future

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discomfort: my undergarments, my only change of clothes and my sleeping bag would be soaked. I simmered in anger and self-pity for several dozen steps as the rain continued to pelt against me. Then, as though a switch was turned on, I suddenly noticed the landscape to which I had been blind thus far. I saw that I was in a field and mist was hovering over the grass. I saw how deep the green was, as it only gets from the moisture of rain. I saw a tree at a distance, standing tall, stoic and graceful against the clouds. Unlike me, it accepted its fate without a ripple of complaint. Everything was beautiful and much vaster than me. In that moment, the extent of my smallness dawned on me: I am at the mercy of a great power that is unseen and untouched but felt very deeply inside. In an instant, the indignation was replaced by awe. Awe at the greatness.

The awe also flowed into the awareness of my own being: not only that I was here—walking, thinking, witnessing such a beautiful sight—but that I was also part of it. Not the *I* who works, performs, judges, and tries to control. Rather, the *I* who is untouched by desires and ideas of individual attainment. The *I* who is worthy and valuable, as a birthright. The *I* who is whole, loving and loved. The *I* who is infinitely small and yet infinitely worthy at the same time. In that moment, peace descended upon me and I felt that everything was as it should be.

And, as it is with life, I could not stand there in the rain forever. I started walking again. Eventually, I stopped in a tiny café and worked on sewing the poncho together. A pilgrim found me there and explained he didn't think my repair attempt would work. But I knew that whether it worked or not did not matter—because everything was as it should be.

True Connection

There is another piece to the story. The poncho that ripped wasn't really mine.

On my first day of the walk, after settling into the bare hostel and finishing up handwashing my clothes, I was faced with the unnerving emptiness of time. I had nothing to take care of, no other chores to do and nowhere to go. I grabbed a book I had packed, relieved to have something to do, and sat in the yard. Before I had even opened the memoir, though, a pilgrim who was draping her clothes on the line struck up a conversation with me. "Don't worry," she said in a jolly tone, "you'll get used to doing nothing. We all do." And she smiled. She had been walking for a week already when I joined. I returned her smile nervously, thinking that I would not survive the void. After all, wasn't *being busy* the precise meaning of *being alive*? We continued to talk and she introduced me to some of the friends she had made on the Way. I saw that, just as she had said, the other pilgrims were comfortable doing nothing. I joined in—stiffly.

The conflict between my habit of constantly doing and the reality that there was nothing much to do was very unsettling. However, my discomfort began to dissipate as I witnessed the pilgrims, learned from their

pace and respected their rhythm. That first evening, I was invited to help prepare dinner with the hostel's small community of pilgrims. A typically rushed and mechanical chore became a collective affair that spread over a few hours. A combination of curiosity and respect prevailed as we got to know one another—not through the armor of what we did for a living, but in the unavoidability of who each of us truly was. Paradoxically, it is precisely what I feared—"*doing nothing*"—that allowed us to carve depth into time by settling into each other's presence. In this way, day in and day out, the emptiness of time became a profound source of replenishment. We connected through sharing not only our tasks but also our personhood. It is not that the friendships we developed or the community we weaved were idyllic and perfect; far from it. It is that the connections were raw and true because we could not escape into *doing* and because our daily experiences of awe opened our hearts.

It is through such true connection that I came to possess the poncho. When one of the pilgrims found out that I didn't have one, he clearly felt compassion for the future-me who would get wet, and gave me an extra poncho he had. It was that gesture of kindness, and the ripping of his poncho, that led to my deep experience of awe in the rain.

Back Home

During the three weeks we were together, the pilgrims and I had numerous encounters with kindness, connection and spirituality. We called them the "gifts" of the Camino. Because of the gifts—which gave me a sense of completeness and wonder—I once expressed to a pilgrim that I wanted to stay on the Camino forever. The wise pilgrim answered: "The *real* Camino starts when you return home and bring the lessons you learned back into your real life."

I think about those words often. I have not managed to bring the Camino home as much as I would have hoped after all these years. I remain future-oriented, I find myself nearly always *doing* and not enough in connection. But as Parker Palmer says, it is part of the human condition for there to be a gap between where we are and where we want to be. I have grown more patient and more forgiving with myself over the years as I inhabit that gap. While there is no fully arriving at where we want to be, there is a striving. Moments of connection—to true self, to others or to greatness—awaken our striving. It is precisely to revive that striving, which runs deep in all of us, that I chose to share this story with you. ■

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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FINDING COMMUNITY IN A FISHBOWL

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KEYWORDS: Palliative care; Remembrance rounds; Memorial rounds

We meet for rounds every morning at 8:30am in a large boardroom past all of the clinics and offices. It is not easy to find the first time, so we forgive new learners if they are late on their first day with us. The room has large windows on both sides—looking outside, and looking into the hallway—so it has become known as "The Fishbowl". The outside windows face the far wing of the hospital, but the local neighbourhood is also visible along with green space. Sometimes, if you look across the way and up one floor, you might see someone holding a brand-new baby as they pace along the maternity unit. I always sit facing the outside windows. The natural light is so lovely that we hardly ever turn on the harsh fluorescents. This gives the room a peaceful atmosphere that lets our early morning eyes adjust, softening the room for what is to come.

Sometimes we are boisterous coming into the room, especially on Monday mornings. There can be a lot of chatter and catching up—both personally and about patients and how they fared over the weekend. There can be anywhere from 10 to 16 people around the table depending on how many learners we have that block—Fellows, Residents, and Medical Students. The constants are the Attending Physicians, the Nurses, and me, the Social Worker.

We are the Palliative Care Team. After medical updates have been shared, new consults acknowledged, and the list has been run, we take time to remember the patients that we have had the privilege of caring for who have died since last we met. Everyone has an equal voice at the table, but never more than when it is time to remember. Laptops are closed, pens are put down, and phones are turned over or tucked away. We pause to listen, to share, and to honour. This time is calm and not rushed. Sometimes the person sharing needs a moment to gather their thoughts or wipe a tear—we sit quietly together in this space and share our humanity. We pass the tissues. We thank each other for speaking.

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There are no real rules for remembering, but we try hard to focus on the non-medical anecdotes and remember people for who they were, not just their illness. We remember their families, often worrying about how they will cope back in their real lives outside of the hospital. We share our successes and our challenges in caring for each person, and what we may have learned. We recognize that patients come with histories, with baggage, and with complicated stories and relationships. Some patients are surrounded by so many people that it can be hard to get close to their beds, and some patients are alone the whole time they are with us. Some palliative care patients have only begun their lives, while others tell us that they have tied up loose ends and are ready.

In our Fishbowl, we share stories of what our patients have achieved in their lives—their incredible adventures and experiences; how they loved and met their partners; losses that have shaped who they are; the devotion of family and friends who have been at their bedsides; and connections to their faith or spirituality, their careers, and the challenges they experienced in their lives. Some patients share so much, and some very little. Sometimes we connect with a patient or their family so deeply, and sometimes we lament that it felt like no connection was made at all. Whether we knew them for only a short time, or through many hospital admissions, we take time to remember everyone.

We share these stories and feelings so freely because we know that the room will be quiet and no judgement will be felt. We see each other as the compassionate humans that we are; humans who have chosen to care for people at the end of their lives. We share this compassion with each other—and hopefully with ourselves, too—as we remember our patients and those who came before them; as we remember our own inevitable losses. As long as there is respect for each other and respect for the people that we are speaking about, we are nurturing a community of safe space. When we sit quietly in our Fishbowl with the door closed and hands stilled, with the buzz of the busy hospital far removed, we are a community of reverence and compassion, where time has slowed down for a short while.

I wonder if people think that we just cross patients off our list when they die and simply move onto the next? I do not think we could do this work if that was the practice. And I do not know where we would put all of the grief… it has to go somewhere. And so, we protect this time in which we can share the grief openly, read poetry, relay a funny story, wonder if we could have done better, and say goodbye properly.

We know so much about so many of our patients because we take the time to ask. Good palliative care is patient-centred with a focus on quality of life as defined by the person themselves. Decisions are made with patients and their chosen people and often depend on a person's values, goals, and personality. Quality of life for one person can mean something completely different for another, and the care we provide means asking those questions and finding out who a person is in order to provide whole person care. We focus on who they are while they live to journey with them toward a (hopefully) good death.

Our Fishbowl community is never the same from one week to the next, but it remains compassionate and dedicated to remembering. The people in the room change due to different schedules and rotations, but the shared dedication to our patients and acknowledgement of what a privilege it is to care for them is the constant. The Medical Student's voice matters just as much as the Attending Physician's, the Nurse's as much as the Resident's. And mine matters too, as a non-medical member of Allied Health. Anyone and everyone can remember our patients, and that lack of hierarchy contributes to being a community. The work is hard, and the days can be heavy, but taking the time to acknowledge these truths and to remember each patient, together, helps us to take care of ourselves and each other before we ready ourselves to meet our next patients. ■

Biographical Note

Sarah Silverstein is a hospital Social Worker in Oncology and Palliative Care. She recently completed the Foundational Certificate in Narrative-Based Medicine from the University of Toronto's Temerty Faculty of Medicine, which has rekindled her love of writing and sharing meaning through stories. Sarah is striving to keep compassion in every healthcare story, and is proud to be one of the Schwartz Rounds Facilitators at her hospital. This is her first publication.

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ARE WE "REAL FRIENDS"? SEARCHING FOR COMMUNITY IN MEDICAL ANTHROPOLOGY

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KEYWORDS: Ethnography; Nephrology; Care; Research; Anthropology

When I think about community in whole person care, I think about Roy.

Roy was a Black, gay American Veteran and a founding member of the first LGBTQ+ church in his city of birth, where he practiced his Christian faith with other queer people for over fifty years. He was a decorated go-go dancer in his youth and received many trophies and accolades for his characteristic charm, good looks, and gilded fashion sense.

Roy was a singer, dancer, tailor, charmer, and sarcastic smartass. Always donned in his signature black-and-white two-piece tracksuit and black cap, Roy reprimanded me many times with a cavalier glare and a stern, *Luvvvvvie…*

It was clear what he meant by that warning: I was talking too much and asking too many questions. Every time, though, I was forgiven with a barking laugh and a tender pat on my hand. Roy was of cantankerous mind and tender soul, which quickly endeared him to the people around him.

I met Roy at an interesting and intimate time in his life. Roy, willful and radiant as he was, was facing imminent kidney failure. I came to know Roy in a research context, working with him as a medical

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anthropologist on an ethnographic research study focused on care for patients with very advanced chronic kidney disease who forgo dialysis.

In-center hemodialysis is the predominate approach to treating kidney failure, in which treatments usually last 4 hours and occur 3 times per week, although there are different forms of dialysis that can be done at home or in specialized facilities. Dialysis can offer relief from some symptoms of kidney failure and extend the lives of many who receive it. But for older and sicker patients, the amount of “added life-time” gained with dialysis can be small while quality of life declines.[1]

Life on dialysis can feel circular, unending, and difficult; it is, of course, not the right choice for everyone.[2] Ultimately, about 7 percent of people with kidney failure elect not to do dialysis and pursue conservative kidney management instead.[3] Conservative kidney management is a holistic, person-centered approach to caring for those with stages 4 to 5 advanced kidney disease who do not want to pursue maintenance dialysis.[4] The focus is on relieving symptoms and maintaining independence and function through medicines, lifestyle changes, and other services.

There are many reasons why one might not choose to treat their kidney failure with dialysis. Values besides longevity are an essential element of whole person care and often go underappreciated in clinical environments where life-extending therapies remain the norm. After all, most Americans get their healthcare in a financially incentivized medical system that prioritizes longevity over other meaningful healthcare values, like comfort, quality of life, or independence.

My research team believes it is possible to make care more person-centered and better resourced for those who do not wish to pursue dialysis. Our research participants help make this vision a reality by volunteering their reflections, experiences, and time with us.

Enter: Roy (and many others, so far).

As part of our ethnographic work, I survey and interview patients about many things: their hopes, fears, and dreams for the future; reflections on their health, the care they receive—what works well, what doesn’t—and what they wish was different. I survey and interview their caregivers and providers. I look inside their medical records to extract chart notes, lab values, and other care-related outcomes like rates of hospitalization, hospice, and intensive care.

Patients invite me to join them in a variety of healthcare settings, such as when they receive care in a clinic or are admitted to the hospital. They show me what it is like to live as a person with kidney disease—I am invited into their homes, and on occasion their workplaces, to spend a part of their days with them.

This juxtaposition of immersing myself deeply within whole-person experiences of illness, contrasted with my external status as a health systems researcher, underscores a persistent fault line underlying my professional identity. I ponder often: to which community do I belong?

Our research team has a running joke that most of us are “certified clinical nobodies.” The implications of this in terms of community, and what it means for people like me to participate in whole person care, are vast.

Like many healthcare professionals, I know my way around hospitals, sit in clinic rooms, and spend hours with patients. I sleuth around medical records and document findings. I debrief visits with providers, present work at medical conferences, and laugh at the punchline of kidney puns.

But I do not wear a white coat; I am not involved in direct patient care. I do not diagnose, treat, nor rehab the patients I work with. I do not call patients with good or bad news. I cannot provide medical advice.

Like other researchers, I work under stringent oversight, am beholden to strict laws around patient information, and keep up to date on best clinical research practices. I publish, present, and push for change. However, as there are many kinds of research, important distinctions are quickly flattened by the title “researcher”.

And finally, like many other anthropologists doing ethnographic work, I am a kind of friend, a sort-of companion. I am familiar with participants’ homes; I know where they keep their coffee mugs. I park in their driveways, admire their family photos, and shake the hands of their children and grandchildren. I talk with them in waiting rooms and cafeterias. I witness as they wrestle with what it means to experience kidney failure. Ultimately, I help reconstruct the meaning of all this data put together to “throw light on the issues” with which our team is concerned.[5]

Qualitative researchers and anthropologists have long been wrestling with what it means to spend extended time in the lives of participants contending with emotionally-charged phenomena. This kind of study necessarily brings the lives of the researched into a sensitive social landscape with the “ambiguity of the researcher who plays a (purported) nonparticipant role”.[6] Purported, indeed. I am often, involuntarily and voluntarily, *participating*, both in the social worlds I observe, and in whole person care more generally.

Through my experience as an ethnographer, I have realized I cannot truly belong to something I cannot fully experience. My belonging in community is parsed out and incomplete. And yet it is incredibly meaningful to find belonging, however temporary, in many spaces, with many people, in many contexts.

I spent some time in the home of a participant named Nora, who faces many barriers to care. Nora lives alone, two and a half hours from both medical centers where she receives care. When she enrolled in the study, I was the first person she had invited into her apartment in over eight years. We spent time together cleaning it up in preparation for an upcoming inspection that she was very worried she would fail.

I told myself that this time together spent was a “day in the life”; that time together, so long as I was invited, is an important element of our data collection. When I was there, we talked about her health, yes, but we also talked about other things: her faith, her life as a nurse, her time overseas, her strained relationships. We played music and hummed Christmas carols. And we cleaned.

The process was sweaty and arduous; I was physically participating in Nora’s life, and it made me feel proud and helpful, but disoriented. We were most certainly beyond the scope of non-participant ethnographic observation. I felt the boundaries between researcher and *me* blurring. One anthropologist writes, “Doing fieldwork is a personal experience. Our intuition, senses, and emotions…are powerfully woven into and inseparable from the process.” [7]

One evening, Nora called and left me a voicemail, wanting to add an addendum to a recent interview. In her message, she shared her thoughts for a minute or two before closing with, “Thank you. Appreciate you very much. And I kind of wish you weren't on the study because then we could be friends. I mean real friends. All right, talk to you later. Bye.” Her voice sounded very sad.

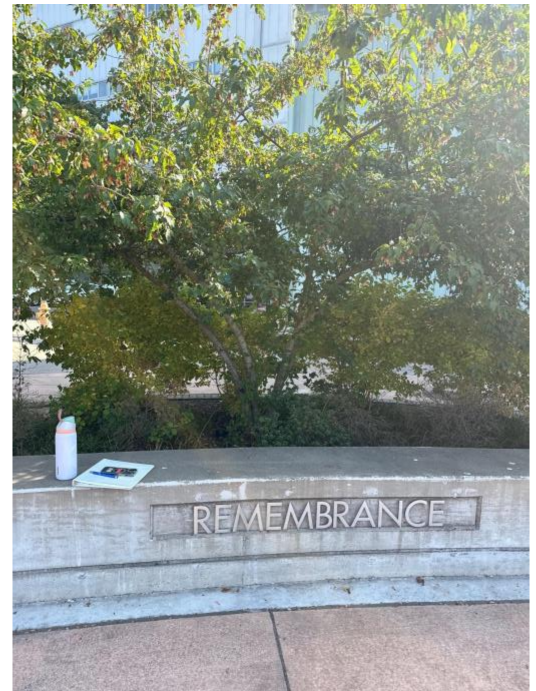
I wondered: Am I a “real” friend? The thought made me cry. I occupy some liminal social position: researcher, colleague, friend, companion, observer, stranger? ‘The girl from the kidney research’, they often call me. I can fix nothing; I can change nothing. I am a non-member of their care team, a fly-on-the-wall, a caring witness. But not, perhaps, a “real” friend.

Roy joined our study a month before he enrolled in hospice, as he was contemplating Washington’s Medical Assistance in Dying (MAID) program. I watched as he actively reconciled what it meant to have advanced kidney disease and forgo dialysis. He felt ready to die. But he also loved people, just as he loved living. He made it emphatically clear: he did not want to go before it was time. But he did not want to hold on to life.

He asked a lot of questions about how he would know when he was ready to die. The hospice nurses gave him simple answers: *You will just know. You will feel a difference in yourself*. I could see him struggle not knowing when that time would be. Roy liked to be in control. Choosing to forgo dialysis and instead enroll in hospice, and MAID, without knowing exactly what the end would look or feel like when it comes, gave him a sense of empowerment and control over the end.

Conservative kidney management confronts us with our own assumptions, biases, and beliefs about how to live and die. Kidney failure throws into sharp relief the irreconcilable paradox of death—that we will die—and yet that death is often understood as a failure. Roy did not see it that way. He had a community waiting to welcome him in death, and he was eager to join them. To die on his own terms would indeed be a great success.

One sunny August morning, I was sitting in the lobby of the primary care clinic, after Roy invited me to attend a routine visit with him. I had alerted his provider that I would be there, and we were both expecting Roy any minute—he was always extremely punctual. His provider came out to the waiting room a few minutes after the hour. In looking at her face, I knew that Roy was not running late. I felt a strange, irrepressible grief rising in my chest.



Later, I sat down in the center of the hospital courtyard on a concrete bench imprinted with the word ‘*REMEMBERANCE’*. I cried, feeling Roy missing from the flurry. I was gutted that my small corner in his vast, expansive life was now devoid of purpose; my role complete in an unfinished job abruptly ended by his passing.

No one noticed me sitting there, it seemed; my tears reflected an untrained disciple of medicine. I felt there was something truly pathetic about me on that bench that would likely repel people away from the area, away from me. The stained red streaks on my cheeks reflected my inexperience with loss in a professional setting, in this medicalized place. All that signaled me as a worker and not a visitor was my government badge hanging around my neck, an emblem of my professional role that somehow felt deeply personal.

What would I have said, should someone have stopped to ask what was wrong? “I just lost a patient” feels untrue. Roy was not just “a patient” to me, nor “mine” to lose. He was a collaborator, a co-conspirator, an interlocuter. He was familiar to me in a whole-person way, in the way where I knew what mattered to him outside of this place.

Roy was looking forward to dying, eager to be reunited with Jesus and his mother. He yearned for heaven, and told me so emphatically, repeatedly, and enthusiastically. I yearned to know if he had made it through the gates of Heaven like he so desperately wished.

That morning, I felt I had been inducted into a club with no living members. Who could I cry with? A member of a care team with no care responsibilities; a life witness with no life ties. I could not call Roy's family. I could not share in my grief with my colleagues. They knew what I meant but they did not feel what I felt. Roy, I felt, was the only one who might have understood this feeling.

When I think of community, I think of all the healthcare workers that know patients as whole-persons but are not necessarily responsible for whole person care. Those that know what it is like to love people who do not "belong" to you, in any normative clinical sense. The relationship I had with Roy and the fondness I felt for him eluded the traditional landscape of relationships in medicine, work, and research. Perhaps the deep loss I feel when patients like Roy invariably pass away or complete the study reveals how the community that I have been seeking in whole person care already exists right in front of me. Our relationship *is* the community.

I attended Roy's celebration of life a few weeks later. The urn that held his ashes gleamed prettily in front of the room. The funeral home was quaint and warm that morning, quiet with just a few handfuls of people who knew and loved him. I slipped into the back. Some of his doctors and nurses came in shortly afterwards and sat in the row just ahead of me; they acknowledged me wanly. We came from the same place, grieved the same person, but we did not overlap beyond that. We did not share the same experience, and were not close to each other in this.

Nonetheless, everyone present sang his favorite songs, shared stories, cried, laughed, and ate together as we quietly remembered and celebrated a beautiful person.

Attendees were invited to take a token of Roy's to remember him by. I chose a small ceramic plate that read, *A day hemmed in prayer seldom unravels*, and hung it by my bedside. Attending his memorial was the closest thing to gathering in community I could think of—the one place I could think of to honor the whole-person that I knew Roy to be. And still, as I mingled and answered the question, "So, how did you know Roy?", the lonely feeling inside me did not budge.

My participation in "whole person care" as a medical anthropologist and ethnographer thwarts community in the traditional sense. I wonder if there will ever be a day where I feel in community with others like me; I ask my therapist about this often. Are there classes for people like me? Affinity groups? Focus groups? Online groups? Groups, groups, I keep looking for groups. Who will understand me? However, no matter how lonely I sometimes feel, I possess a deeply unshakeable sense that I am never truly alone. Through this work, my participants and I become community to each other as we both seek a place to feel understood. I feel myself in affinity with those who experience this work with me. Because we are, just for a moment, together. ■

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Biographical Note

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A PLACE ON THE SPECTRUM

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KEYWORDS: Community; Whole person care; Autism; Parenting; Neurodivergence; Belonging; Masking; Caregiver experience

When my son was diagnosed with autism spectrum disorder at the age of three, I felt like I had been hit by a truck. He was still the intelligent, loving, curious boy he had always been, but as both his mother and a psychiatrist, I took the assessment results to mean I had failed a crucial test. Trained to recognize these patterns professionally, I felt as though I had missed a trail of breadcrumbs, my senses dulled by a parental fog of denial. To have not seen him fully in his neurodivergence felt like a maternal failure—one I had studied so hard to avoid.

I tried to reorient myself by thinking of the patients and families I supported in my practice. I have sat with many adult children receiving a parent's dementia diagnosis—a diagnosis painstakingly obvious to my assessing eye and yet, almost irrelevant to the devotion already in place. The spoken words did not elevate care, they simply formalized what filial responsibility had been doing all along. Their support system was unwavering, terminology be damned. Perhaps I could not see my own son's diagnosis because I was doing something similar: reshaping my parenting expectations to fill his developmental gaps. Perhaps I had adapted so completely that the "difference" no longer read as difference. It simply read as my child.

Still, I did not find myself on the other side of a child psychologist's desk by accident.

The provider told me my son had "level 1" autism. I had learned the levels by rote in residency, but I had never paused to consider their gamified feel, or the strange way I was meant to accept this placement on a ludicrous scoreboard as reassurance. I caught myself longing for the experience of my friends, whose

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children transitioned with ease, followed instructions, and neither eloped[1] nor became violent with frustration. I resented how they took for granted the simple gift of meeting their child's gaze, and I sullied my thoughts with regret, self-blame, and pity in response.

Like many parents, I tried to seek understanding through community. I joined support groups. I attended hospital-based parenting workshops. I arrived ready to learn and ready to be held. What I could not have anticipated was the quiet loneliness that came from being on the margins of a very broad spectrum: too "typical" to fully belong in some spaces, too "atypical" to feel welcome in others. The initial triumph of my "good" parental instinct to seek an assessment was swiftly complicated by guilt. Guilt about accessing scarce services for a child whose level (and whose privilege) implied he already had a head start in the game. Visual schedules, first-then language, timers, reinforcements, and transition toys became lifeboats in a storm, but only because I could afford the lift. I worried my son would one day internalize this sense of partial belonging and be forced to navigate these rushing waters alone.

When I began to share my son's diagnosis with friends and family, reactions were mixed. Some coyly professed to "knowing" the whole time. Others offered superficial reassurance that was ableist-coded: *He doesn't seem different*, or, *Isn't that just all toddlers*? The diagnosis, intended to create clarity, instead operated like a social disturbance. It unsettled other people's sense of normal, and the fastest way to restore equilibrium was to invalidate what had been named. We had been given a language for our experience and then gently—repeatedly—invited to speak less of it.

At other times, my son's diagnosis was met with the faint edge of unfairness, as though support was a prize that needed to be earned rather than a scaffold offered in equity. I felt this judgment most sharply when a dismayed mother, whose own child had been assessed as not having autism, questioned why we sought professional help in the first place, when he *seemed to be doing just fine*. I thanked her for acknowledging our son's developmental gains and gingerly explained the difference between seeking support and seeking a diagnosis. What we needed was guidance; what we ended up with was a label. I began to wonder if naming neurodivergence as pathology reinforced the existence of an unachievable normal—an invisible "ideal child" against whom all children are measured. The reaction to his diagnosis felt less like curiosity and more like an unspoken referendum on everyone else's children.

Autism treatment became a loaded journey in itself, and I often found my psychiatrist and parenting selves swirling in constant tension. What was the goal, exactly? To reward compliance at the expense of

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[1] Eloped: leaving a safe area or a caregiver's supervision unexpectedly, which can pose safety risks. (Reference: *Centers for Disease Control and Prevention. Wandering (Elopement). Available from: https://www.cdc.gov/child-development/disability-safety/wandering.html*)

autonomy? To teach my child to mask[2] his differences rather than be understood? The pressure to conform wasn't always demanded outright. It was often conveyed with subtlety through community expectations: a thousand gentle cues that rewarded him most when he looked least like himself. It arrived as praise for being "good," relief when he was "easy," and the unspoken lesson that belonging was conditional on how little space he took. The diagnosis had me monitoring my motives as vigilantly as I monitored his needs. I could not pretend I didn't want my son's life to be easier, yet I struggled with how to help him resist becoming a project of erasure. If he was happy, safe, and connected, did it really matter how closely he tracked the curve?

While none of this has altered the unconditional love I have for my son, it has reshaped my experience of parenting. Raising a child is a profoundly vulnerable state—one where expertise doesn't carry a shield and where the volume of recommendations (and judgment) can drown out intuition. For now, I am learning to hold guidance lightly, to follow my son's cues, and to protect the bright way he moves through the world from being dimmed in the name of appearing "typical." What he needs most isn't the right label or the right workshop, but the steady experience of being welcomed without having to prove he deserves it. Community is less a place to fit in and more a practice of making room. I want my son to know belonging that asks only one thing of him: to be himself. No one should have to mask to be met. ■

Biographical Note

Dr. Kayla Simms is an emergency, outpatient, and shared care psychiatrist in Ottawa, Canada, and a faculty member in the Department of Psychiatry at the University of Ottawa. She is a clinician educator and is currently completing the Healthcare Education Scholars Program at the Centre for Innovation in Medical Education. Her clinical and educational work focuses on communication in high-stakes encounters and simulation-based training in verbal de-escalation.

[2] Masking: strategies used by some autistic people to hide or suppress autistic traits to fit social expectations. (Reference: *National Autistic Society. Masking. Available from:* https://www.autism.org.uk/advice-and-guidance/behaviour/masking)

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COMMUNITY AS CARE: SOLIDARITY, WHOLE PERSON CARE, AND LESSONS FROM THE PEER MEDICAL FOUNDATION

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KEYWORDS: Whole person care; Solidarity; Community; Relational ethics

Whole Person Care (WPC) is, at its core, a relational practice, requiring attention to not only symptoms or diagnoses, but to the emotional, social, moral and existential dimensions of patients' lives. However, within contemporary healthcare systems—which prioritize efficiency, specialization, and quantifiable outcomes—the relational aspects of care are frequently marginalized. Healthcare providers committed to WPC often experience a dissonance between professional values and systemic incentives, creating a persistent tension between what is ethically desired and what is institutionally supported.

This structural misalignment has tangible consequences. Relational labour, emotional presence, moral reasoning, and engagement with lived experience are often undervalued or rendered invisible. Clinicians, educators, and health professionals committed to WPC may therefore encounter isolation, moral fatigue, and a subtle erosion of meaning over time. These efforts underscore a critical tension: while WPC

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emphasizes interconnectedness and holistic attention, its practice within fragmented systems can leave practitioners carrying both the ethical and emotional weight of care alone.

Addressing this tension requires more than individual resilience or reflective practice. Sustaining WPC necessitates engagement in forms of solidarity and community that extend relational care beyond the dyadic patient–clinician encounter. Community provides a collective scaffold in which relational and ethical work is shared, acknowledged, and sustained. Solidarity, in this context, is not merely a value or aspirational ethic; it is a practice through which care is reinforced, knowledge is co-constructed, and moral and emotional labour is distributed. Solidarity is not incidental to WPC, it is its animating condition. Without solidarity, WPC risks becoming a solitary moral burden carried by individual clinicians or isolated patients. With it, care becomes a shared ethical project—one in which the recognition of each person's full humanity is sustained not by any one individual's effort, but by a community committed to practicing it together.

Our engagement with the Peer Medical Foundation (PMF) exemplifies the potential of community to sustain WPC in practice. PMF is a peer-led community grounded in solidarity among people living with rare diseases and marginalized health conditions, and the clinicians, educators, and learners who care alongside them. It is neither exclusively patient-facing nor practitioner-facing; it is a shared relational space in which both are full participants. Its co-leadership model deliberately places patients, particularly those from rare and underserved disease communities, alongside healthcare professionals as equal voices in shaping priorities, agendas, and practices. This structure is not incidental but foundational; it enacts the belief that those most affected by illness hold irreplaceable knowledge. Within this environment, relational care is not only supported but co-produced, enabling healthcare professionals, learners, and peers alike to sustain the ethical, emotional, and practical dimensions of WPC over time.

Finding Community in Unexpected Places: Solidarity Beyond Traditional Hierarchies

Even when one is committed to WPC, finding community can be difficult. Medical personnel (physicians, nurses, and allied health professionals), who serve as a patient's first point of contact, often lack the time, tools, or resources to facilitate connections that address the emotional, social, or spiritual dimensions of illness.

It was within this landscape that PMF emerged as an unexpected and vital site of community. PMF members share lived experience with a range of rare diseases and navigate the intersectionality of illness, socialization, gender, and race. Its peer-led structure enables marginalized perspectives to inform advocacy and practice, fostering democratic participation in shaping priorities, sharing knowledge, and co-creating support networks. Community within PMF is not simply the aggregation of individuals; it is relational and

ethical, grounded in the shared recognition of vulnerability across physical, emotional, social, and spiritual dimensions of illness.

Solidarity emerges when the community acknowledges the totality of a person's experience. Medical narratives are enriched when emotional and mental responses, social and spiritual implications, and the lived realities of navigating illness are considered alongside physical symptoms. In rare disease communities, this practice of shared knowledge and advocacy allows for the development of collective expertise, self-awareness, and mutual support. Within PMF, relational care is co-produced. Patients, peers, and clinicians collectively sustain one another, demonstrating how solidarity can extend the ethical and practical dimensions of WPC beyond the clinical encounter.

What Nurtures—and Thwarts—Community and Solidarity

We have learned through our work that community and solidarity do not emerge accidentally. They are cultivated through deliberate relational practices that resist the dominant rhythms of healthcare. One of the most essential of these practices is slowness and presence. In contrast to clinical environments shaped by time scarcity and productivity metrics, PMF creates space to slow down and attend fully to one another. This slowness allows people to be encountered not as cases or problems to be solved, but as whole persons whose experiences deserve careful listening. Scholars of narrative medicine emphasize that attentive presence and narrative exchange foster moral recognition and relational trust [1], particularly in contexts of illness and vulnerability. We have witnessed how simply making time to listen, without interruption or agenda, becomes an act of solidarity.

Another practice that nurtures community at PMF is valuing lived experience as knowledge. Members are encouraged to share personal narratives of illness, care, and marginalization. These narratives are treated as legitimate and instructive forms of expertise. This stance directly challenges what philosophers of medicine describe as epistemic injustice [2], wherein patients' testimonies are discounted due to structural power imbalances. By centring lived experience, PMF creates a space of epistemic justice where people who are often silenced within healthcare systems are recognized as knowers. This recognition not only affirms dignity but also deepens solidarity by redistributing authority across differences.

Marginalized members often bear greater emotional and social risk when speaking openly, particularly around experiences of racism, disability, or rare disease neglect. Without explicit attention to power and inequity, communities risk reproducing the very harms they seek to resist. As theorists of solidarity argue, it requires a willingness to sit with discomfort and to confront structural injustice rather than bypass it.

Solidarity within PMF is further sustained through mutual accountability. Because the community is peer-led, responsibility for care is shared rather than delegated. Members show up for one another, follow

through on commitments, and remain attentive to the relational impact of their actions. Within PMF, this reciprocity is not incidental but constitutive—it is precisely because members hold one another accountable that trust deepens, and solidarity endures. In this context, solidarity remains an ongoing practice, one that requires attentiveness, maintenance, and care.

How Our Understanding of Community and Solidarity Has Evolved

Initially, we understood community primarily as a source of belonging and emotional support. Community meant not being alone and having others who could recognize and validate experiences of illness that were otherwise invisible. This understanding aligns with much of the peer support literature, which emphasizes shared experience as a foundation for connection and coping, particularly in rare disease contexts. At this stage, solidarity felt synonymous with empathy and mutual understanding.

Over time, however, our involvement with the PMF reshaped this understanding. Community came to feel less like a refuge and more like a shared responsibility. Solidarity was no longer only about feeling with others but about acting with them. Members did not simply offer support, they co-created responses to systemic barriers, advocated together, and shared the labour of sustaining one another. This shift mirrors relational ethics frameworks that emphasize interdependence, moral responsibility, and collective care. Through engagement with PMF, we have come to appreciate that community is an active, co-constructed space in which solidarity is practiced daily. It emerges through shared vulnerability, ethical engagement, and attention to the totality of lived experience, including physical, emotional, social, and spiritual dimensions.

Perhaps most significantly, practicing WPC within a community transformed our sense of who provides care. Care was no longer unidirectional or professionalized; it flowed reciprocally between peers, patients, and practitioners. Within PMF, solidarity is enacted when members recognize the moral, emotional, and practical labour involved in caring for oneself and others. Observing and participating in these interactions highlighted how solidarity requires not only attention to similarity but a deliberate willingness to engage with difference. It is in this engagement that ethical growth, relational depth, and moral resilience are cultivated—qualities essential to sustaining WPC

Finally, we have learned that WPC is not a solitary endeavour. Its principles are realized through relational practice embedded in the community. The work of sustaining ethical, relational, and holistic care depends as much on shared accountability and co-created knowledge as it does on individual skill or intention. Through PMF, we have witnessed that community and solidarity are not mere adjuncts to WPC; they are its scaffolding, enabling care to be ethically, relationally, and holistically sustained. Building this scaffolding requires humility and willingness—to be changed by relationships, to follow as readily as to lead, and to allow those most affected by illness and inequity to guide direction and meaning. Solidarity, in this sense,

is not a fixed achievement. It is something we continually choose: a daily practice of showing up, listening without agenda, and remaining open to transformation. WPC is ultimately sustained not by individual habit or professional attitude, but by communities committed to practicing care, together. ■

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Biographical Notes

Salvatore Rotolo is an artist, lifelong learner, and advocate. He has lived experience with disability. As Director of Research, he guides projects to deepen knowledge on topics such as health equity, patient voice, and community-centred approaches to care.

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Leah Sarah Peer is the Founder and Executive Director of the Peer Medical Foundation (PMF), a youth-led nonprofit advancing health equity, inclusivity, diversity and racial justice in medicine. Drawing on her experience as a rare-sibling, and her formation within clinical and academic medicine, she brings an intersectional lens to rare disease education, health equity advocacy and the design of inclusive healthcare systems, guided by the conviction that transformative change in medicine begins when lived experience is not consulted but centred.

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COMING HOME TO COMMUNITY: REFLECTIONS ON WHOLE-PERSON CARE IN A HOSPICE IN INDIA

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KEYWORDS: Whole person care; Community; Palliative care; Reflective practice

Community is often described as a place, a group, or a shared identity. Through my work in palliative care, however, I have come to see community as something more intimate. It is not only where we belong, but how we care for one another, how we bear witness to suffering, and how we remain human in the face of vulnerability. In whole-person care, community is expressed through emotional presence, shared meaning, cultural understanding, and spiritual connection—through relationships that allow healing to occur even when a cure is no longer possible.

My time volunteering at a hospice in the foothills of the Himalayas deepened this understanding. Community revealed itself in everyday acts: conversations at the bedside, shared meals, moments of celebration and grief, and quiet pauses between tasks. What surprised me most was not the strength of community itself, but how quickly I felt myself becoming part of it. This experience challenged my assumptions about belonging, expanded my understanding of whole-person care, and deepened my sense of how I wish to nurture and grow community in my own life and practice.

For me, community is not defined by proximity or similarity, but by presence and reciprocity—it is not simply something we receive, it is something we sustain together. Community is the experience of being seen and held—sometimes quietly, sometimes imperfectly—within a network of relationships that values connection. It carries a responsibility to show up—not only when it is convenient or professionally required, but when it is emotionally demanding. Community means that care is not delivered to a patient but shared with them.

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It recognizes that illness does not occur in isolation; it ripples through families, caregivers, healthcare teams, and broader social structures.

Before my experience in India, I understood community largely within professional boundaries: interdisciplinary teams, institutional affiliations, and defined roles. While these remain important, my time in India revealed a more expansive, integrated vision of community—one where personal and professional identities coexist, and where care flows in multiple directions. I was not only a provider of care but also a participant in a community of care. My presence, listening, teaching and learning were all part of this reciprocal exchange. It reminded me that community thrives when we allow ourselves to be both givers and receivers.

One evening after a long day of home visits, I sat on the hospice rooftop reflecting quietly as the Ganga River flowed below. A nurse noticed my fatigue and wordlessly placed a cup of tea in my hands before sitting beside me. We shared a few minutes of silence, then returned to our tasks. In that small, unspoken act of care, I felt held by the same community I had come to serve.

I was born to Indian immigrants from Punjab, yet I often felt like an outsider within my own extended Indo-Canadian family; my Canadian-ness marking me as just a little different, even at home. One of the most striking aspects of my experience at the hospice was how quickly I felt welcomed into a deeply established community. Despite being an outsider—culturally, linguistically, and geographically—I was received with openness, trust, and generosity. I was invited into patient rooms, family conversations, staff discussions, celebrations, and moments of grief. The warmth and openness with which I was received, not just by the staff but also by the patients and families, created an immediate sense of belonging. What surprised me most was that community at this hospice did not rely on sameness. Staff members came from diverse backgrounds and disciplines—physicians, nurses, social workers, homecare nurses, volunteers, spiritual advisors—yet there was a shared ethos that transcended hierarchy and was more relational. Care was not fragmented by role but woven together by a collective commitment to the patient and their family.

I was also impressed by how extensive community was beyond the walls of the hospice. Through homecare visits, outreach programs, educational initiatives, and partnerships with organizations, the hospice functioned as a living network of care. Patients were not “discharged” from community; they remained connected through ongoing relationships. In visiting patients in their homes—some in modest dwellings or on the street—I witnessed community as an act of reaching outward. The homecare nurses embodied this beautifully. They brought medications and clinical expertise, but just as importantly, they brought time, listening, and presence. Their work illustrated that community is sustained not by grand gestures, but by consistent, compassionate attention.

One afternoon, I accompanied a homecare nurse to visit a young woman with tongue cancer living alone in a tent. The nurse gently assessed her pain, offered medications, and sat with her long enough to hear her story of displacement and loss. In the encounter, I saw how dignity can be restored not through resources alone, but through presence and recognition of personhood.

Whole-person care acknowledges that suffering is multidimensional—physical, emotional, social, spiritual—and that addressing one dimension without the others leaves care incomplete. At the hospice, community was the medium through which whole-person care was made possible. This was evident during group sessions facilitated by a volunteer psychiatrist, where patients were invited to express the emotions they carried about their illness. The creation of a safe, communal space allowed patients to feel less alone in their suffering. I was astonished by the way their vulnerability became the architecture of community. In sharing their fears, their grief, and their small joys alongside their suffering, they were constructing a space where everyone belonged—a space where a deeper communion emerges when we stop hiding our brokenness and discover the cracks are where the light of connection enters.

Community building is also a practice of self-awareness. In their wisdom, the hospice offered meditation sessions to the staff, recognizing that caregivers themselves are whole persons whose emotional and spiritual well-being directly impacts the care they provide. In palliative care, we carry so much—the weight of others' dying, the helplessness of watching suffering we cannot eliminate, the grief that accumulates day after day. This invitation to center ourselves, to recharge emotionally, was not self-indulgence. It was an acknowledgment that we cannot pour from empty vessels, that tending to our own well-being is essential to showing up fully for others.

Family meetings further illustrated the role of community in whole-person care. During one family meeting with a frail elderly woman with advanced Parkinson's disease, multiple generations gathered to speak openly about their fear of losing her. As they took turns sharing their love for her, their memories and anticipatory grief, the room softened. The presence of social workers, nurses, physicians, and family members created a shared holding space—one where no single individual bore the weight of suffering alone. We were there together to connect, to listen and to help the families and one another feel less alone.

Moments of celebration carried the same spirit of connection. During Holi festival at the hospice, patients, families, and staff gathered to mark the arrival of spring, honouring life even in the presence of death. By including patients and families in cultural and spiritual rituals, the hospice affirmed their identities beyond illness; the dying were not separated from the living, the sick from the well, the staff from the patients. This image has stayed with me: colour, music, and laughter filled the courtyard, reminding us that joy can coexist with suffering. This coexistence is at the heart of whole-person care—recognizing that humans need beauty, celebration, and connection.

Vulnerability also played a crucial role. Witnessing difficult conversations—such as discussions about prognosis or impending death—required emotional openness from both healthcare providers and families. Allowing myself to be present in these moments, rather than retreating behind professional distance, strengthened my sense of belonging. I was not merely observing community; I was participating in it. Community was also nurtured through reflection and meaning-making. Educational sessions, staff discussions, and shared learning experiences created opportunities to step back from clinical tasks and consider the deeper purpose of our work. Presenting to nursing students and healthcare professionals allowed me to contribute to the community's growth, reinforcing that community is sustained through both receiving and giving.

These experiences enhanced my sense that community is nurtured by shared purpose, vulnerability, and intentional presence. At the hospice, shared purpose was evident in the collective commitment to dignity, compassion, and patient-centred care. This alignment allowed relationships to form quickly and deeply.

One of the challenges of healthcare is the pressure of time—scheduled appointments, documentation demands, productivity metrics. My experience in India reminded me that community requires a deliberate slowing down. Time and space must be created, not found. Creating space is necessary for connection and that means being willing to pause—to sit, listen, and resist the urge to "fix." It involves recognizing that presence itself is a form of care. I learned time for connection is not merely a logistical issue but a value-based choice. In India, extended family meetings, long home visits, and unhurried conversations were prioritized, even within resource limitations. This intentional use of time communicated to patients and families that their stories mattered. It also fostered trust and deepened relationships. This lesson has influenced how I approach my work. In palliative care, taking the time, making eye contact, allowing silence, and being attentive to emotional cues are as important as any medical intervention.

Community is not about having everything we need; it is about sharing what we have, about creativity born of compassion, about refusing to let limitations become excuses for abandoning people. The hospice community also included those who have been marginalized—people whom society had abandoned: the person experiencing housing insecurity living in a tent, the frail elderly woman living alone, the grieving granddaughter who is unmarried and living in poverty. To care for the whole person is to attend to the relational spaces in which people live, suffer, and find meaning. Whole-person care requires that community be intentional about inclusion and responsive to vulnerability. This inclusivity challenges us to confront inequities and to extend care beyond comfort zones—opening doors, widening circles, and making room. Community is what happens when we stop performing our separateness and allow ourselves to be woven into the fabric of shared human experience.

Before my experience in India, I viewed community largely as something that supported care. I now understand community as care in and of itself. It is the context within which healing, meaning, and dignity become possible. Growing community begins with modelling the values we wish to cultivate: empathy, curiosity, humility, and respect. Community emerges through trust and shared humanity. It is sustained not by perfection, but by showing up, again and again.

My time at this hospice in India changed me. I arrived as a specialist coming to share expertise, and I left as a student who had learned invaluable lessons about community, wholeness, and care. As I move forward, I carry these lessons with me—that growing community is an act of hope, that it is a commitment to connection, that whole-person care is inseparable from community, and that in nurturing community, we nurture our shared humanity. I discovered that community is like coming home to a place I did not know I had been missing. ■

Biographical Note

Camille Munro is a palliative medicine specialist based in Ontario and Nova Scotia, Canada. Her clinical and academic interests include whole-person care, equity and inclusion in healthcare, and the relational dimensions of palliative practice. She also has an interest in global palliative care and reflective medical education, informed in part by volunteer work supporting the hospice and community-based care initiatives in India. She is deeply grateful to Dr. Taranjit Singh and the staff at Ganga Prem Hospice for the experiences that shaped this work. Outside of medicine, she enjoys spending time with her three adult children and her grandson, as well as reading, travelling, and being outdoors—especially by the ocean.

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BUILDING COMMUNITY IN THE SHADOWS OF STIGMA

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KEYWORDS: Whole person care; Oncology patients; Counseling psychology; Social stigma

The Weight of Silence

During my years of service as a clinical nurse at *Tikur Anbessa Specialized Hospital*—Ethiopia's primary governmental referral center and largest oncology hub—I witnessed firsthand the intersection of medical complexity and human suffering. As families traveled from every remote corner of the country to reach us, I came to understand the deep social burdens they carried. This perspective helped me to address the psychological *shadows* of cancer and treat the patient as a whole person.

Working in this context, I witnessed a kind of suffering that medicine alone could not heal. Patients faced a crushing weight of financial crisis and cultural stigma. For women with cervical cancer, the struggle was particularly difficult. They often faced an offensive discharge—a persistent, foul-smelling vaginal leakage caused by the necrosis of the tumor—which, coupled with deep-seated shame, often led to total isolation. In the quiet hallways of the ward, I saw women who would not look me in the eye, their shoulders hunched as if trying to disappear into the hospital walls, especially for those from rural areas where cancer is sometimes whispered about as a "curse" or a divine punishment. At first, I felt entirely alone in my frustration, helpless against the sorrow of patients who were not just fighting for their lives, but for their dignity.

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The Sanitary Pad: A Turning Point

My perspective changed because of a 47-year-old woman from a rural area who came to our procedure room. She was in distress, suffering from heavy discharge, and had no sanitary pads. I remember the way her hands shook as she tried to adjust her clothes and felt heavy with embarrassment. I gave her my own products, and this small, human gesture broke her silence. She wept—not the loud weeping of a sudden injury, but the slow, heavy tears of someone who had been holding a mountain inside. She told me that her husband and family had isolated her, forcing her to use separate utensils and refusing to eat with her because they feared she was "contagious."

I realized then that her anxiety was more painful than her physical tumor. With her quiet consent, I invited her husband into the room. I did not want him to feel accused; I wanted him to feel informed. I provided health education on the medical realities of her condition and the importance of emotional support. I stayed with them until I saw the tension leave his shoulders, waiting for that moment of realization when he understood that his wife was not a danger to the family, but a woman in need of his love. The moment he finally reached out to touch her hand was the moment the 'community' of their marriage began to be restored.

Seeing them leave the hospital together—not as a patient and a fearful stranger, but as a couple reunited in understanding—was a profound victory. The smile she offered me was evidence of a "prescription" more powerful than any medicine I could provide; it was the smile of someone brought back into the *warmth of her community*.

Restoring Dignity and Health

When I shared this experience with my colleagues during lunch time—sitting over shared plates of "*injera*" —the isolation I had been feeling vanished. We realized we all shared a collective "moral injury" from seeing our patients suffer in ways medicine alone could not reach. We realized that we, the nurses, were also a community that needed to heal itself by helping others. At that moment we all reached the conclusion that this scenario can be a powerful reminder that a simple, human intervention can be more curative than the most complex clinical procedure. Therefore, together, we began to grow our own quiet community of care, rooted in the principles of Whole Person Care—treating not just the disease, but the human being in their specific cultural and financial context. Thus, we turned two things into action.

1. The Sisterhood of Care: We recognized that many patients, especially those arriving from remote rural areas, were completely unprepared for the physical realities of their condition. Many did not know about sanitary pads and relied on a single piece of traditional textile like "*Netela*". This was not only a matter of dignity but a serious health risk, as it exposed their already vulnerable bodies to infection. For this reason,

we began a small, quiet practice of saving one or two sanitary pads from our own personal supplies to give to these women. We were not only providing a resource, we were providing a lesson in self-care and safety. Moreover, it was our way of telling these women that their health and their honor mattered to us.

2. Bridging the Awareness Gap: We expanded our morning health education sessions to integrate psychological support alongside clinical information. We transformed our waiting areas into *classrooms of compassion*. We achieved this by rearranging the seating to encourage dialogue and using our morning health education sessions to openly discuss the emotional needs of oncology patients. Our goal was to target the specific cultural misconceptions that fuel social stigma. By educating caregivers on the emotional needs of oncology patients and correcting the misconceptions about the disease being “contagious”, we fostered a community of informed and compassionate support around every patient.

Restoring the Spirit

To treat the disease effectively, we must first stabilize the patient’s psychological state. A body cannot heal if the mind is in a state of stress. While many of my peers chose to specialize further in clinical oncology nursing, I realized that my greatest impact would come from stepping into the *shadows* that medicine often ignores—the space where physical care meets mental health.

Consequently, I decided to upgrade my career by pursuing a Master’s in Counseling Psychology. This was not a move away from nursing, but an expansion of it. Today, working in a large private hospital, I integrate these two worlds. My nursing background provides the clinical foundation, while my psychological training allows me to address the deeper, invisible battles that oncology patients face.

I have learned that a cancer diagnosis often triggers a total collapse of identity and a loss of self-confidence. Beyond the physical trauma, many patients enter a profound spiritual struggle, wrestling with feelings of unworthiness or engaging in a 'fight with God' to find meaning in their suffering. My role now is to hold space for these existential crises, helping patients rebuild their sense of self and find peace amidst the storm. I have realized that Whole Person Care is about more than clinical recovery; it is about restoring the spirit of the human being behind the patient. When we foster community, we prove to the patient that we are one and the same. ■

Biographical Note

Selamawit Kinfu Alemayehu is a clinical nurse and counseling psychologist based in Addis Ababa, Ethiopia. During her years of service at Tikur Anbessa Specialized Hospital, she witnessed the deep social burdens and profound isolation carried by oncology patients—shadows that medicine alone could not heal. Having completed her Master’s in Counseling Psychology, she now integrates clinical nursing expertise with

psychological training to address the invisible battles her patients face. Currently, she practices in a large private hospital where her work focuses on "Whole Person Care". She helps oncology patients rebuild their self-confidence, and bridge the gap between clinical treatment and the life they cherish with their loved ones.

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COMMUNITY AS CARE: WHOLE PERSON BEREAVEMENT PRACTICE IN A RURAL HOSPICE SETTING

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KEYWORDS: Whole person care; Rural hospice; Bereavement; Compassionate communities

Practicing bereavement care in a rural hospice setting means practicing care in full view of community. It is shaped not only by clinical practice, but by the relationships, histories, and shared spaces that define community life. The individuals and families I support are not anonymous, nor are their losses contained within clinical encounters. They are neighbours, volunteers, caregivers, former colleagues, and friends of friends. Their shared grief does not begin or end at the hospice door. It continues in grocery stores, at community events, and within shared histories that stretch far beyond the moment of death.

I work as a bereavement services provider and thanatologist with Madawaska Valley Hospice Palliative Care in a rural and remote region. Over time, I have come to understand community not simply as the setting in which whole person care occurs, but as a central element of the care itself. In this context, grief is relational, cumulative, and visible. Community both sustains and complicates the work, offering deep connection while also requiring thoughtful boundaries, ethical awareness, and ongoing reflection.

Madawaska Valley Hospice Palliative Care exists to provide compassionate support that enhances quality of living and dying. In a small but mighty community, this mission is lived through relationships rather than isolated interventions. Care unfolds over time across caregiving, dying, and bereavement, and is shaped by place, familiarity, and shared responsibility.

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This paper explores how practicing bereavement care within a rural hospice setting shapes an approach to whole person care in which community itself becomes an active participant in supporting caregivers, the dying, and the bereaved. This approach aligns with growing recognition within palliative care that compassionate communities play a vital role in supporting people through illness, dying, and bereavement.

Rural Community: Strength, Tension, and Care

Rural communities are often described by what they lack, including proximity to services and specialized resources. Yet one of their greatest strengths is relational. Everyone knows everyone. When someone receives a life limiting diagnosis or experiences a death, the community is often ready to help. Meals appear, driveways are cleared, rides are offered, and quiet check-ins happen without being asked.

This readiness to care exists despite geographic challenges and limited formal supports. People take care of their own. In many ways, community fills gaps that systems cannot.

At the same time, this closeness carries complexity. Visibility is constant. Shopping, attending community events, or simply being out in public often means encountering people who are caregiving or grieving. Managing boundaries when everyone knows what you do can be challenging. There is little anonymity, and grief does not stay neatly contained within scheduled appointments.

Rather than resisting this reality, I have learned to work within it. I am clear with families that I will not approach them in public, but that they are welcome to approach me. This practice respects privacy while acknowledging shared space. Over time, it has fostered trust and clarity, allowing relationships to remain both ethical and human.

Working in a small community means holding ongoing awareness of those who are grieving. I often say that I have “eyes on people”, not in a clinical sense, but as part of relational care. I notice who has withdrawn, who may be struggling, and who might benefit from gentle outreach. Running into families in the community is something I am accustomed to. Rather than feeling intrusive, it often reinforces trust. People know who I am, what I do, and that I am part of the same community. This familiarity can feel grounding, particularly in times of loss.

Ethical practice in this setting relies less on physical distance and more on clarity, consent, and respect. Boundaries are maintained through open communication and mutual understanding, allowing care to remain both professional and deeply human.

Whole Person Care Across Time

In rural hospice work, bereavement care rarely begins after death. Much of my role involves supporting individuals and families through anticipatory grief—the emotional, relational, and existential losses that begin long before a loved one dies.

Community based anticipatory grief sessions invite caregivers to name what is already changing, including roles, identity, routines, and hopes for the future. These sessions normalize emotions such as guilt, relief, exhaustion, fear, and love. Naming these experiences early helps caregivers feel less alone and less ashamed. It also acts as burnout prevention, particularly in rural settings where caregiving responsibilities are often carried out with limited respite and long travel distances.

Whole person care in this context means recognizing grief as emotional, social, physical, and existential. It means making space for meaning-making during the long goodbye rather than postponing reflection until after death. It also means understanding that caregivers remain embedded in their community throughout illness, not removed from it.

Meaning, Memory, and Shared Ritual

Meaning-making is central to bereavement care, particularly in rural communities where grief is woven into daily life. Alongside groups and workshops, we offer tangible and experiential supports that allow grief to be carried beyond shared spaces and into homes and seasons.

Take-home memory kits, which include commemorative ornaments, invite individuals to engage with remembrance privately and on their own timeline. These kits acknowledge that grief does not end when a session concludes, and that meaning often unfolds quietly through ritual, reflection, and repeated return.

Seasonal gatherings, such as ‘Hope for the Holidays’, create gentle communal spaces for remembrance during times when grief may feel intensified. These gatherings emphasize connection, creativity, and presence, without pressure to share or perform. Hope is framed not as the absence of grief, but as something that can exist alongside love and memory.

More recently, we offered our first three day widows retreat, recognizing the profound identity shifts that follow the death of a partner. This immersive experience allowed participants to share stories, rest, reflect, and witness one another’s grief over time. In a rural context, where widows often remain in the same communities they shared with their partners, this sustained approach supported both healing and belonging.

Supporting meaning-making in rural communities also involves strengthening the ability of the broader community to respond to grief. Workshops such as ‘How to Support a Grieving Friend’ and ‘How Can You Help When Someone You Care About Is Dying’ offer practical guidance for friends, neighbours, coworkers, and extended family members who want to help but often feel unsure how. These sessions focus on listening without fixing, acknowledging loss without comparison, respecting privacy, and continuing support beyond the earliest stages of illness or bereavement.

Lessons from Rural Practice: Compassionate Communities and Caregiver Resilience

One of the clearest lessons from rural hospice and bereavement work is the essential role of compassionate communities in supporting people to live and die well. Most Canadians report a preference to remain at home at the end of life [1]. This wish is deeply relational and relies heavily on family members, friends, and neighbours.

While professional services play an important role, the majority of day-to-day care occurs outside formal systems. Caregivers often support their loved ones with limited respite, long travel distances, and few specialized resources. Without intentional support, they are at significant risk of exhaustion, isolation, and burnout. Whole person care must therefore extend beyond the patient to include those providing care long before death and well into bereavement. Creating compassionate communities is not about assuming communities will simply know what to do. It requires teaching, modelling, and normalizing care.

Resilience in this context is not about coping alone or being strong, it is about awareness, connection, and permission to receive help. By helping caregivers and community members map their circles of support and remain present beyond the initial crisis, communities become better equipped to serve their own.

Rural hospice and bereavement practice offer important lessons about whole person care. When community is recognized not as a backdrop but as an active participant, grief support becomes relational, continuous, and grounded in place. In rural hospice practice, community is not simply *where* care happens, it is *how* care happens. ■

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Biographical Note

Jenna Stamplicoski is a thanatologist and Bereavement Services Coordinator with Madawaska Valley Hospice Palliative Care in rural Ontario, Canada. Her work focuses on whole person grief support, anticipatory grief education, and building compassionate communities that support caregivers, families, and the bereaved. She develops and facilitates community based grief groups, caregiver education sessions, and retreats designed to address the unique needs of rural and remote populations. Jenna is grateful to work alongside the dedicated staff and volunteers at Madawaska Valley Hospice Palliative Care. She lives in the Madawaska Valley with her husband and three children on a small sheep farm.

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THE COST OF CARING: COMMUNITY AND STEWARDSHIP IN SUSTAINING WHOLE PERSON CARE

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KEYWORDS: Whole person care; Emotional labour; Compassionate communities; Stewardship

> "The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to walk through water without getting wet."
>
> —Dr Naomi Rachel Remen, Kitchen Table Wisdom, 1996

Whole person care is often described as an ethic of focused attentiveness: an orientation that honours the physical, emotional, relational, and existential dimensions of human experience. It invites practitioners to attend not only to symptoms and treatments, but also to meaning, relationships, identity, and dignity. Yet, embedded within this orientation is a reality that is less frequently named: the cost of sustaining such focused attentiveness over time.

For me and many practitioners, whole person care is a sustained professional commitment. Our work calls for practitioners to honour the multi-dimensional aspects of the human experience. It demands emotional presence, moral discernment, relational responsibility, and ongoing reflexivity. This does not exist at the margins of clinical work; it sits at its core.

While deeply meaningful, it cannot be sustained by individual endurance alone. Caring deeply and responsibly is—by nature—depleting, not because practitioners are insufficiently resilient, but because the work accumulates unique stressors that impact well-being. In my work within home palliative care, I see this depletion as the *cost of caring*, accrued through repeated exposure to suffering, ethical tension, and

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emotional labour, particularly when practitioners are asked to embody values that systems do not always structurally support.

When left unnamed or individualised, the cost of caring manifests as exhaustion, moral distress, burnout, fatigue, or quiet withdrawal. However, when recognised, named, and shared, I believe it can become the foundation for a more sustainable practice. But achieving this requires both the support of the communities in which we practice, and deliberate stewardship to hold the emotional and moral weight of caring.

The Cost of Caring: Emotional Labour and Moral Distress

The concept of emotional labour provides a helpful lens for understanding the often invisible work embedded in whole person care. Beyond technical competence, practitioners are expected to regulate emotions, remain empathically attuned, and offer presence in the face of uncertainty. Hochschild's [2] description of emotional labour as the management of feeling to align with occupational expectations resonates strongly with caring professions, where emotional regulation is expected yet rarely acknowledged.

In end-of-life care, I observed how this labour is intensified when holding space for difficult conversations, anticipatory grief, and ethical complexity. Practitioners are not merely witnesses to suffering; they are stakeholders in relational processes involving loss, hope, and meaning-making. This work requires repeated emotional and moral engagement that standards of practice alone cannot support.

Moral distress further compounds this cost. Jameton [3] described this as a common experience faced by practitioners—of knowing what ethically appropriate care requires, yet being unable to act accordingly. Constraints such as time pressures, resource limitations, or organisational priorities often marginalise relational work. The resulting dissonance is morally injurious.

What struck me was that these experiences are often internalised and privatised. Practitioners may interpret fatigue or disengagement as personal inadequacy, rather than as signals of cumulative strain (both emotional and moral). Sustainability is then framed incorrectly as an individual responsibility rather than a systemic concern. Consequently, it obscures the structural dimensions where this cost could be shared.

Community as Collective Stewardship

My early understanding of stewardship was shaped by my training in social work and by organisational discourse. In that conventional paradigm, stewardship was largely associated with resource management, governance, and professional standards. While these elements remain important, I have come to see that such an understanding is incomplete if it does not attend to the emotional and relational realities within

which care is delivered. Through my work in palliative care, stewardship has gradually taken on a different meaning for me. I have come to understand it less as the management of systems and more as the shared responsibility of holding the moral and emotional weight of caring. In practice, this means recognising that the cost of caring cannot be carried by individuals alone. When practitioners attempt to sustain whole person care through personal endurance, the work quietly becomes isolating and unsustainable.

Community, in this sense, functions as a form of collective stewardship. In teams where reflective dialogue is normalised, practitioners are less likely to equate responsibility with overextension or self-sacrifice. Instead, difficult experiences—ethical tensions, emotional labour, uncertainty—can be acknowledged and shared. Community becomes a relational space in which complexity can be held without isolation, allowing practitioners to remain accountable to their values without carrying the full burden alone.

My experience has also taught me that such communities do not arise spontaneously. They require intentional cultivation and leadership that value reflection alongside action. In fast-paced clinical environments dominated by urgency, productivity, efficiency and excellence, spaces for dialogue are often the first to disappear. Yet it is precisely these spaces that sustain whole person care over time.

Leadership plays a central role in stewarding these conditions. When leaders listen carefully, remain open to difference, and allow uncertainty to be explored rather than quickly resolved, they model a culture in which reflection and relational responsibility are legitimate parts of professional work. Equally important is the flexibility to adapt structures of care as contexts change, while remaining anchored in shared values of compassion, collaboration, and shared responsibility.

Where such stewardship is present, the emotional and moral weight of caring becomes distributed across the community of practitioners rather than absorbed silently by individuals. In this way, stewardship is not merely organisational oversight; it is the ongoing cultivation of relational conditions that allow whole person care to remain shared, sustainable, and humane.

Congruence, Boundaries, and Shared Responsibility

Sustainability in whole person care rests on congruence—the alignment between espoused values and lived practice. Incongruence arises when practitioners are asked to embody compassion, presence, and relational depth without adequate relational or structural support. Over time, such dissonance becomes corrosive.

Community plays a critical role in restoring congruence. Through shared reflection and dialogue, practitioners can surface ethical tensions, negotiate boundaries, and redistribute responsibility. Boundaries, in this context, are not barriers to care; they are ethical structures that protect both practitioners and

patients. They clarify what is possible, what must be shared, and what must be relinquished. From a values-based leadership perspective, such boundaries are not acts of withdrawal, but expressions of compassion—toward patients, colleagues, and the self—because they preserve the conditions necessary for care to remain attentive, ethical, and sustainable.

Shared responsibility is particularly important in mitigating moral distress. When ethical tensions are held collectively rather than privately, practitioners are less likely to internalise systemic constraints as personal failure. Community thus functions as both an emotional and moral resource, supporting practitioners to remain engaged without becoming overwhelmed.

Leadership has a crucial role here. When leaders model boundary-drawing, reflective practice, and vulnerability, they legitimise sustainability as a collective value rather than an individual weakness. In doing so, they steward not only services, but the conditions that allow whole person care to take place and individuals delivering this care to thrive.

Practice Vignettes: Stewardship, Endurance, and the Limits of the Self

My understanding of stewardship deepened not only through leadership responsibilities but also through lived experience. As my professional responsibilities expanded to include leadership, supervision, programme development, organisational initiatives and teaching alongside clinical work, I came to recognise that stewardship does not apply only outwardly—to systems, teams or services—but also inwardly, to the practitioner.

Whole person care relies fundamentally on the practitioner's presence, clinical judgment, and emotional availability. The self is not incidental to practice; it is a vessel through which care is delivered. When that instrument becomes depleted through chronic overextension, the integrity of care are compromised—often gradually and almost imperceptibly.

This became clear to me during a period when I was deeply invested across multiple domains of work and life. Alongside carrying complex clinical cases and supervising colleagues, I was involved in developing new bereavement initiatives, contributing to organisational planning, supporting wider community programmes, and taking on teaching engagements. At the same time, I was navigating motherhood and caregiving responsibilities within my personal life.

Outwardly, I appeared competent, compassionate, and committed. Inwardly, I sensed a gradual narrowing. My emotional spaciousness was shrinking; sustaining focus and attentiveness became increasingly difficult, and I carried a persistent sense that I was holding more than I could meaningfully metabolise.

In retrospect, there was no single crisis. Rather, the strain accumulated through small, incremental decisions: agreeing to “just one more” responsibility, holding ethical tensions privately, remaining available to accompany one more family, and postponing reflection in the name of urgency. Without recognising it, I had come to equate stewardship with endurance, and commitment with constant availability.

It was only through reflective supervision and trusted peer conversations that this pattern became visible—not as personal failure, but as a signal that work could not be sustained in isolation. Stewardship of the self required a reorientation: clarifying where responsibility genuinely lay, naming what could be shared, and drawing boundaries without self-reproach. Far from withdrawing from whole person care, this recalibration allowed me to remain present without depletion. This experience reshaped my understanding of leadership: if sustaining practice requires such deliberate attention even within supportive environments, practitioners working without strong professional communities are particularly vulnerable to internalising the cost of caring as a private burden.

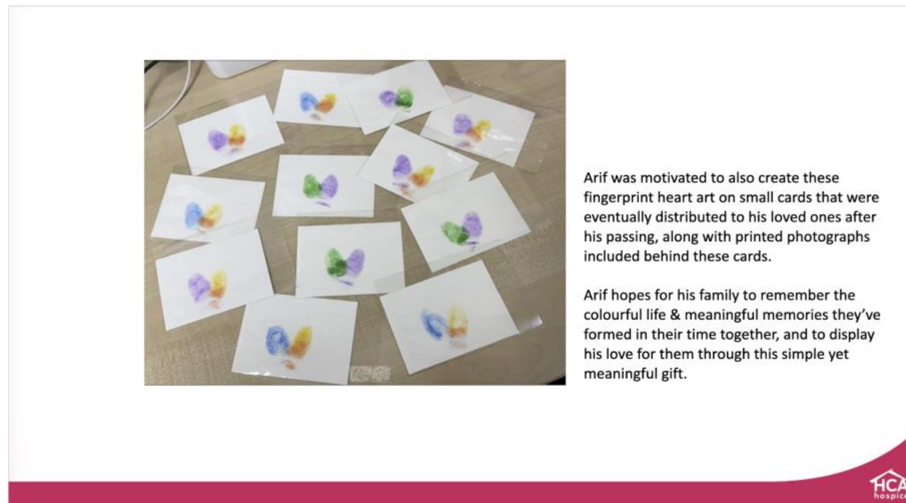
One example of collective stewardship emerged during a multidisciplinary team meeting in which a colleague shared the emotional weight of supporting a 27-year-old male patient and his family as they navigated his rapid deterioration, anticipatory grief, and impending death. The case carried a particular moral and relational weight for the team, confronting us with the profound dissonance of accompanying a young adult whose life was ending far earlier than expected. Rather than focusing solely on clinical management, the conversation widened to acknowledge how the emotional labour of this case was affecting the physicians, nurses, and medical social worker directly involved in his care.

As the discussion unfolded, it also became apparent that the case was affecting members of the wider team who had not participated directly in the patient’s care. Listening to the account, colleagues leaned in with quiet attention, carrying the emotional weight of the situation vicariously through the act of witnessing. The team created space not only to discuss care plans but also to hold the emotional and ethical tensions surrounding the impending death of a patient whose life was ending far too soon.

In that space, responsibility began to redistribute itself. Colleagues held space for tears, acknowledged transference, and named the moral distress that accompanies caring for patients whose suffering feels particularly unjust. What shifted was not only the management of a single case, but the recognition that the emotional weight of care did not belong to one practitioner alone.

At the close of the meeting, the medical social worker invited the team to participate in a small act of remembrance and solidarity. Each member of the team placed their thumbprints on a deck of cards, gradually forming a multicoloured collection of hearts. The artwork was later presented to the patient as a simple expression of care, appreciation, and acknowledgement of how his life had touched those who

accompanied him in his final months. The gesture resonated deeply with the patient, Arif. In the weeks that followed, he began creating his own cards using similar thumbprint impressions alongside family photographs. After his death, these cards were given to his family members as parting gifts—small, intimate tokens of connection that carried both memory and love.



Experiences such as this reshaped how I came to understand the role of community in sustaining care. Within clinical teams, collective stewardship redistributes the emotional and moral weight of caring so that practitioners are not left to carry it alone. Yet the same principle extends beyond professional settings. If the sustainability of whole person care depends on shared responsibility within teams, it must also depend on the wider communities in which care, grief, and healing unfold.

This recognition gradually shifted how I approached both leadership and practice. I began to see that sustaining whole person care required not only supportive teams, but also the intentional cultivation of communities where care could be shared, witnessed, and carried collectively.

Growing Sustainable Communities of Care

In recent years, my work has increasingly focused on cultivating communities that embody these principles—among practitioners, teams, and within the broader caregiving ecosystem. Team-based leadership—often enacted through small, interdependent leadership trios within sub-teams—alongside supervision spaces, mortality rounds, reflective forums, bereavement groups, and community-based rituals, has demonstrated how shared spaces can absorb and redistribute the emotional weight of care. These practices reflect a collaborative, values-based approach to leadership, where responsibility is intentionally shared across roles and relationships, reducing isolation and supporting collective resilience.

One illustration of how community redistributes the cost of caring emerged through an open bereavement support group developed for individuals who were socially isolated and experiencing profound loneliness following loss. Many participants entered the group with limited social networks, describing grief as something they carried almost entirely alone. The group was intentionally structured as an open, non-time-limited space, emphasising shared presence over therapeutic progression or outcomes.

Over a period of approximately twelve to sixteen months, a noticeable shift occurred. A core group of bereaved individuals began to form—participants who moved from tentative attendance to sustained engagement. Through repeated encounters, shared stories, and mutual recognition, members began to articulate not only pain and loneliness, but emerging meaning in their grief. Connection replaced isolation; suffering became something that could be witnessed and held collectively rather than endured privately.

Over time, peer leadership began to emerge organically within the group. Members who had initially attended primarily to receive support gradually took on relational roles of their own, initiating parallel social activities beyond the formal group sessions. These included visiting their loved ones' niches together, sharing home cooked recipes that carried memory and meaning, and organising meals and gatherings to mark anniversaries or festive occasions. Such activities were not designed or directed by professionals, but arose from members' growing sense of mutual recognition and care.

Through these shared practices, grief became woven into everyday life rather than confined to designated therapeutic spaces. Acts of remembrance, nourishment, and companionship offered members ways to remain connected—to those they had lost and to one another—without needing to explain or justify their grief. In this way, care was no longer concentrated solely within professional roles, but began to circulate within the community itself, held and expressed through ordinary yet deeply meaningful gestures.

What emerged was not the resolution of grief, but a shared capacity to live with it. This capacity was marked by connection rather than isolation, contribution rather than passivity, and a quiet form of transformation in which members moved from being recipients of care to co-creators of a sustaining community.

What this experience reinforced for me is that sustainable bereavement care is not only delivered; it is grown. When community is intentionally stewarded, the emotional weight of grief—and of caring for grief—can be shared, allowing both practitioners and bereaved individuals to move from isolation and loneliness toward connection, agency, and purpose.

As I reflected on this experience, I recognised strong parallels with Kellehear's concept of Compassionate Communities, which frames care, loss, and dying as shared social responsibility rather than tasks reserved for professionals alone [4, 5]. What I observed within the bereavement group was not simply peer support, but the gradual re-socialisation of grief—where meaning, remembrance, and care were held within everyday relationships and communal practices. In this way, care extended beyond formal service boundaries and became embedded in ordinary acts of presence, reciprocity, and mutual responsibility.

Situating this work within a compassionate communities lens highlights that sustaining whole person care depends not only on professional expertise, but also on nurturing social capacities for care within communities. When grief is held collectively, the emotional and moral weight of caring is no longer borne solely by practitioners. Instead, care circulates across relationships, allowing both professionals and community members to remain engaged without depletion.

This reflects a public health understanding of care, where healing and adaptation occur within networks of relationship rather than through isolated professional encounters. Practitioners themselves are part of this ecology. Without community, the cost of caring becomes unsustainable; with it, care becomes a shared and enduring practice.

Importantly, growing community does not require uniformity. The most resilient communities are those able to hold differences—across disciplines, cultures, roles, and level of experience—while remaining anchored in shared values of dignity, compassion, and presence. When such differences are acknowledged and engaged rather than minimised, community becomes not only a source of support, but a site of shared learning and ethical growth.

Attending to differences in this way is itself an act of stewardship. It requires leaders and communities to cultivate humility, curiosity, and dialogue rather than conformity. Within such relational conditions the emotional and moral cost of caring can be shared collectively rather than internalised by individuals, allowing care to remain both humane and sustainable [1, 3].

Conclusion: Stewarding the Conditions for Care to Continue

The cost of caring is a reality to be stewarded. Whole person care will always require emotional labour and moral courage. The critical question is whether this cost is borne in isolation or held collectively.

Community serves as the quiet architecture sustaining this care. Stewardship must extend beyond systems to include the self. Through congruence, boundary-drawing, and shared responsibility, practitioners can remain engaged without depletion. In attending to these conditions, whole person care endures not as heroic individual effort, but as a shared, ethical, and sustainable practice.■

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Biographical Note

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MOVING CLOSER TO THE GROUND

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KEYWORDS: Care; Companions; Belonging; Purpose; Everydayness

The Rhythm of an Ordinary Day

Located in the coastal town of Kozhikode in southern India, the Institute of Palliative Medicine is grounded in the conviction that relief from suffering and living a dignified life—towards its end and in death—are fundamental human rights. The institute's patient care services, which include outpatient, inpatient, and home-based care, are offered for free, and its work extends to building compassionate communities that place caregiving at their core. These services run alongside a constant rhythm of other activities: educational, communal, spontaneous. A closer look at an ordinary day helps to make these activities, and the communities that form around them, visible.

A regular day at the institute unfolds predictably, almost ritualistically. The doors open at 7:00 AM, first to the kitchen and facilities teams who quietly set the tone for what follows. By 8:00 AM, outpatient staff begin to gather; by 8:30 AM, the ward opens and settles into motion.

The inpatient ward, meanwhile, never fully pauses. Morning shift changes overlap with night shift handovers; the home-care team reviews schedules and departs by 9:30 AM; administrative desks come alive; volunteers disperse across outpatient and inpatient areas; and patients and caregivers begin to arrive. Familiar families move with ease, sometimes searching for the volunteer who walked with them during previous visits. New registrants pause at reception, then are gently guided onward. This apparent clockwork has slowly evolved through years of trial, adjustment, and persistence.

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As the day stretches on, the campus fills with students, interns, trainees, and observers. The day progresses with almost ritualist tea breaks and a hearty lunch. Outpatient services wind down by late afternoon, staff begin to leave, and the inpatient ward shifts into its night rhythm. These transitions are unremarkable, yet essential—small acts that quietly hold the system together.

It is against this steady choreography that particular moments stand out, asking to be examined closely.

A Radio, and the Shape of Care

One such moment was experienced by a colleague during a routine home visit. The institute's home care programme runs six days a week, reaching nearly 500 patients across Kozhikode. Whilst all visits feature memorable moments, this one stands out because of a simple radio. Murali, who lives with his wife in a single room at his sister's home, has lived with diabetic peripheral vascular disease for many years. Once active, his world has gradually narrowed—now bedbound, with his eyesight slowly receding. Yet he recognises the home-care vehicle instantly by sound alone.

During one visit, after wounds had been dressed and medications adjusted, the nurses lingered—as they often do—talking casually. Murali mentioned that his old radio had stopped working. Nearly obsolete in an age of smartphones, the radio was for him a companion: a source of music, news, and connection to a world beyond his room. What seemed trivial to most was central to his sense of agency and belonging.

When the team returned to the institute, this detail travelled, not just among nurses, but through volunteers as well. The next day, a volunteer arrived with a new radio. Handing it to the home-care nurse, all she said was, "This is for Murali."

In moments like these, the sense of community crystallises and a koan-like question emerges: where does a team begin, and where does it end? Here, care moves fluidly across roles—nurse, driver, volunteer, patient, family member—without needing formal coordination. Community reveals itself not as structure, but as a response.

Unexpected Companions in Care

Back on campus, patient care over the past year has unfolded alongside a major renovation—the institute's first since its founding. Construction dust, scaffolding, and freshly completed spaces exist side by side.
I recall a chance conversation with the project's lead electrical engineer. He remarked, almost incredulously, that he had never worked at such a site before. Decisions that were routine elsewhere—drilling, hammering, wiring—required repeated deliberation here. Labourers, he noticed, often paused mid-task, glancing toward patient rooms to gauge whether the noise might disturb someone resting nearby.

Over his year-long association with us, the engineer invited every staff member personally to his wedding. The following day, he sponsored lunch in our kitchen—a meal shared by patients, families, staff, and volunteers alike. As the renovation wound down, we hosted the architects, engineers, and labourers for an evening of gratitude. Laughter, singing, and shared food softened boundaries that had already begun to blur. Community, here, had quietly expanded to include those who arrived with tools. This expansion brings along its own nuances of how far community can stretch, and what tending to it requires from those at its centre.

Blooming in Care

Among our largest and most visible communities of volunteers are university students, who feel at home navigating our campus. On one particular day, the campus buzzed as usual, but this time, alongside the familiar university faces, a group of high school students had come to visit. After a brief tour, these students gathered for an introduction to palliative care. The teenagers listened intently as we spoke about suffering and care. When asked whether they knew someone at home who needed care, nods rippled across the room. Then one boy raised his hand and asked, “What can I do?”

A month later, at their school carnival, these students ran a stall raising funds for our organisation. One student, we learned, had sold an expensive perfume to contribute to the collection. This small act signified something larger: an instinct, perhaps, of what community asks of us all—not grand gestures, but a willingness to give what one has.

Meanwhile, the older student volunteers had a clear task: reorganising our hall in preparation for an upcoming conference. A huddle formed near the main building: staff, acquaintances, and a group of eager young volunteers. Together, they moved to the hall, sorted through a mountain of items, and ferried everything back using trolleys. There was music, laughter, playful stumbles, confusion, troubleshooting, and quick resolutions. Students paused to exchange jokes with nurses, guided families to the outpatient ward, and dashed into the kitchen to request a milkshake instead of the usual tea. Before heading back home, they lingered until sundown.

Through their continued presence within our palliative care space, these students provide psychosocial care for patients and families, contribute to training and education, and organize campus activities and fundraising campaigns. They continuously contribute to spontaneous ventures, such as transforming our old home care bus into a coffee shop. Interestingly, this student community is in constant flux. Graduates move on to new frontiers, making way for those who follow. Yet, what is striking is how few truly leave.

Watching them, I find myself less curious about why they are here and more attentive to what they are helping to create: a more compassionate world, both within and beyond our palliative care space. In them, I find deep conviction for the present and hope for the future.

Becoming, Through Community

These ordinary rhythms, happenings, and connections merge to form a larger expression of community—one that does not announce itself but simply is.

Within the Institute of Palliative Medicine, community is a heterogeneous constellation: families across socio-economic contexts; healthcare professionals; students from law, medicine, nursing, social work, and the arts; retirees who once led colleges or police departments; non-clinical staff; visiting academics; political figures who come and go. The list contracts and expands rhythmically, much like a beating heart. The unifying pulse is care.

In a space with such porous boundaries—where people enter and exit frequently—I used to wonder how accountability and responsibility were factored. During an early conversation, my mentor offered an idea that has stayed to become more concrete over time: human beings, one could argue, are moved to act in the face of suffering; most often when environments enable them to do so. Perhaps, especially so, in radical spaces that are open to everyone—spaces where one is welcome not only to look around, but also encouraged to look inward; to explore, together, how connection may be made, held, and shared.

I am now convinced that community is nurtured through small intentions and everyday actions. There may be many ways to prepare this dish, but the recipe almost always includes openness, collective intention, and shared meaning. This sense of community, however, is not one of constant warmth or effortless harmony. With heterogeneity comes difference, tension, and negotiation. Yet what emerges is hard earned intimacy. Community can only be sustained by attending to these nuances. It takes multiple actors to allow roots to entangle deep and the canopy of care to spread wide.

Very often, as I walk onto campus each morning, I find myself reflecting on what draws me here. Leaving behind a decade in physical sciences, I entered these new spaces of care with conviction, but also with looming uncertainty. Over time, a quiet awe has settled in. It is directed toward this spirit of community—amongst so many diverse actors, each holding unique potential, and moving together. What this community has offered me is purpose in increments: of learning how to do and be, together.

Perhaps this, finally, is what community has instilled in me—a sense of becoming, shaped not alone, but in relation. ■

Biographical Note

I came to palliative care from chemistry. After nearly a decade in academic and research science, I found myself drawn toward questions that perhaps laboratories could not quite hold. I am currently associated with the Institute of Palliative Medicine – WHO Collaborating Centre, Kozhikode, where I contribute to collaborations and research projects while slowly learning to volunteer in palliative care.

This piece is also an expression of gratitude—to the institute and the community it has grown—and to Saif Mohammed, whose camaraderie has a profound impact on me as I find my footing in this space.

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FINDING AND FOSTERING COMMUNITY IN THE PRACTICE OF WHOLE PERSON CARE

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KEYWORDS: Whole-person care; Healthcare leadership; Reflective practice; Psychological safety; Interprofessional collaboration

Practicing whole person care often begins quietly. It begins not with a protocol or framework, but with an internal orientation: a commitment to attend to the full humanity of those we care for, and to our own. For clinicians, educators, and healthcare leaders alike, this commitment shapes how we listen, how we tolerate uncertainty, and how we remain present in moments that resist easy solutions.

Across my professional life, I have carried this commitment through multiple roles and environments: as a clinician working directly with patients and families; as an educator supporting learners navigating their professional identities; and as a healthcare leader responsible for shaping systems that influence how care is delivered. In each setting, whole person care has felt both deeply meaningful and, at times, unexpectedly solitary.

Healthcare environments, whether clinical units, academic institutions, or administrative offices, are increasingly shaped by time pressures, documentation requirements, fiscal constraints, and performance metrics. Within these systems, relational work can become invisible. The acts of listening deeply, acknowledging suffering, and holding complexity rarely appear in productivity reports or strategic dashboards. As a result, those who hold whole person care as central to their practice may find themselves quietly questioning whether their values are fully supported.

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It took me time to recognize that this sense of isolation was not a personal shortcoming. It was a signal. I was trying to sustain work that is inherently relational without adequate relational support. What I needed, though I did not yet have language for it, was community.

Whole Person Care as an Individual Commitment

Early in my career, I understood whole person care primarily as an individual responsibility. I focused on cultivating reflective practice, emotional awareness, and clinical competence. I worked to become more attentive to patients' narratives, more comfortable with ambiguity, and more transparent about the emotional dimensions of care.

In clinical encounters, this meant pausing when conversations became difficult rather than redirecting them. In teaching environments, it meant inviting learners to reflect on how clinical experiences affected them personally, not only technically. In leadership settings, it meant advocating for policies that recognized staff wellbeing as integral to quality care.

This individual commitment served me well in many respects. It allowed me to build meaningful relationships and to experience moments of authentic connection, even within constrained systems. Yet over time, the limits of this framing became clear. Without spaces to share experiences, voice doubts, and reflect collectively, the emotional weight of the work accumulated. I began to wonder whether practicing in this way was sustainable, or even welcome, in environments that seemed to reward speed and certainty over reflection and presence. I rarely voiced these concerns aloud. I assumed others were managing better. In hindsight, this silence reinforced the very isolation I was experiencing.

Discovering Community in Practice

The most meaningful experiences of community in my professional life did not arise from formal initiatives, though structured programs can play an important role. They emerged instead in ordinary moments across diverse environments.

In a hospital corridor after a difficult clinical outcome, a colleague once paused long enough to ask how the day had affected me, not just operationally, but personally. In a faculty office, a learner shared uncertainty about their capacity to remain compassionate in the face of repeated suffering. In a leadership meeting, a senior administrator quietly acknowledged the moral strain experienced by frontline staff.

Amongst these, one conversation stands out. After a particularly challenging period, I found myself speaking with a colleague whose role differed significantly from my own. What began as a logistical discussion shifted into a shared reflection on grief, responsibility, and the tension between institutional

expectations and personal values. There was no attempt to fix the situation. There was only recognition. That recognition itself was restorative.

Conversely, I have worked in environments where whole person care was prominently featured in mission statements and strategic plans, yet where little space existed to speak openly about moral distress, vulnerability, or emotional impact. In those settings, the language of whole person care was present, but the relational infrastructure was absent. I often felt more alone there than in places where whole person care was never explicitly named.

These experiences clarified something essential: community cannot be assumed based on shared terminology. It must be enacted through listening, reciprocity, and sustained attention to one another's lived realities.

Conditions That Nurture Community

Across clinical, academic, and administrative contexts, I have observed several conditions that consistently nurture community in whole person care.

Psychological safety is foundational. Community flourishes when individuals can speak openly, not only about successes, but about uncertainty, emotional responses, and mistakes, without fear of judgment or reprisal. In leadership roles, I have learned that psychological safety is modeled before it is mandated. It grows through consistency, transparency, and a willingness to acknowledge one's own limits.

Shared reflection is equally vital. Whole person care invites us to examine who we are in relation to our work. When reflection occurs collectively, whether in debriefs, peer conversations, or interdisciplinary rounds, it normalizes emotional experience and reduces isolation. Naming moral distress together transforms it from a private burden into a shared human response.

Mutual respect across roles and disciplines further strengthens community. In healthcare settings shaped by hierarchy, relational wisdom can be overshadowed by positional authority. I have come to value spaces where lived experience, of nurses, physicians, allied health professionals, administrators, and learners alike, is treated as legitimate knowledge. When expertise is broadened in this way, community becomes a space of learning rather than comparison.

Forces That Undermine Community

Just as community can be nurtured, it can also be quietly eroded.

Time pressure remains one of the most pervasive challenges. Across the environments I navigate, clinical care, academic teaching, and organizational leadership, schedules are dense and margins thin. When relational work is framed as secondary to productivity, opportunities for connection diminish.

Hierarchical cultures can also impede authenticity. In settings where authority is equated with certainty, admitting uncertainty or emotional impact may feel risky. Individuals retreat into professional personas that prioritize self-protection over openness.

Perhaps most insidious is the normalization of emotional detachment. When caring deeply is framed as a liability, practitioners may distance themselves from patients and from one another. In such contexts, whole person care becomes an internal, private practice rather than a shared endeavor.

Making Space for Community

One of the enduring tensions in my practice has been how to create space for community within already full roles. Over time, I have come to understand that community does not always require extensive time; it requires intentional presence.

Some of the most meaningful connections I have experienced occurred in brief exchanges: a few minutes of undivided attention, a shared silence after difficult news, a thoughtful follow-up message. Their significance lay not in duration, but in quality.

As a leader, making space for community has also required difficult choices. For many years, I equated commitment with availability. I accepted responsibilities aligned with institutional priorities, often at the expense of reflective space. Gradually, I realized that protecting relational capacity sometimes meant declining opportunities, not out of disengagement, but out of stewardship for the aspects of work that sustain both staff and patients.

In practical terms, fostering community has involved facilitating peer check-ins, encouraging reflective dialogue in team meetings, celebrating collective achievements, and creating forums where interdisciplinary perspectives are genuinely welcomed. These actions may appear modest, yet over time they reshape culture.

An Evolving Understanding of Community

My understanding of community has shifted significantly. Early in my career, I associated it with belonging to a defined group: a department, a discipline, an institution. While such affiliations matter, they are not sufficient.

I now understand community as relational rather than structural. It is grounded in shared values rather than shared titles. It may include colleagues, learners, patients, mentors, and brief encounters that leave lasting impressions. It may be transient or enduring. What defines it is not permanence, but presence.

Community does not eliminate systemic constraints or prevent moral distress. It does not remove the complexities inherent in healthcare. What it offers instead is companionship; a reminder that the weight of caring work is carried collectively, not individually.

Community as Renewal and Responsibility

In a healthcare landscape marked by increasing complexity and strain, fostering community is not optional: it is essential to sustaining whole person care.

As a healthcare leader, I have come to see community-building not as an aspirational ideal, but as a professional responsibility. Creating environments where staff feel seen, heard, and connected strengthens resilience, engagement, and ultimately the quality of care provided to patients. When relational infrastructure is intentionally cultivated, whole person care becomes embedded in culture rather than dependent on individual endurance.

Community asks only that we show up: imperfectly, honestly, and with willingness to listen. In doing so, whole person care becomes a shared practice capable of sustaining us over time.

For those of us committed to this work, fostering community is both a responsibility and a gift. It allows us to practice with integrity and compassion. Most importantly, it reminds us that while the work may at times feel solitary, it was never meant to be carried alone. ■

Biographical Note

Sarvesh Mohan is a healthcare leader with experience across health system leadership, clinical operations, and education in diverse care settings. His work focuses on advancing quality improvement, patient safety, healthcare innovation, and workforce wellbeing. He is pursuing a Master of Business Administration, is a Certified Health Executive, and has completed executive education from Harvard University in healthcare leadership and coaching. He also holds a postgraduate qualification in Healthcare Administration and Service Management and a Bachelor of Dental Surgery, and is committed to whole person care, reflective practice, and interprofessional collaboration.

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GO WEST

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KEYWORDS: Women; Medicine; Wellness; Narrative medicine; Taos

This poem was written to commemorate the Taos Writing and Wellness Retreat for health professionals hosted by the University of New Mexico School of Medicine in August 2025.

Gather a womb of women
a phalanx of physicians
a mission of mothers.

When one sneezes
they all will say Salud in a chorus.
When one cries
one will hold out a hand,
the one beside her will embrace her shoulders
and another will offer a box of tissues.
When one makes a devastatingly droll quip about toxic masculinity in medicine,
they will all practice a kegel and howl in delight.

Early morning musing meditations while running rhythmically down dry dusty and solitary sidewalks
followed by brief blithe banter
with the base camp babysitter or second string spouse
not seeking permission to persist
but wiping the mental white board filled with curious questions
and guarded guilt for their elective absence,
clean.

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Then rejoin the coven, carefree
refreshed and refocused
with a meeded mug of coffee and cream,
and recommit to unraveling demons, doubts and dreams.

The fall of democracy is stressing us out.
As if “Back to School” isn’t enough for this time of year,
the pleasant and painful paths we are pursuing
whether trodden or untrodden soil
are exhausting.

We co-miserate and co-celebrate in alternating patterns.

Have you ever seen a bevy of bodies come together in a circle,
a circumference tightly made
shoulder to shoulder
and suddenly synchronized
sit
supporting each other?

This is what we strive for.
Each gives and receives.
Novices find their nuanced niche of self knowledge to share.
Even designated teachers learn.

With outstretched arms we wave goodbye, each holding threads of the tapestry
woven from our words.

Go west young woman,
the old you will not return,
Or rather
you will return renewed. ■

Biographical Note

Rachel Gagen grew up in Richmond VA, and earned a BA in literature at Yale. She attended medical school at the University of Virginia and completed her pediatric residency at the Medical College of Georgia. She has lived with her family in Virginia as a full-time pediatrician since 2007. She is a writer of 3 books, hundreds of unpublished poems and now one published! She will complete her certificate in Narrative Medicine from Columbia University in 2026. She is one of those people who loves coconut, the Oxford comma, and long walks in the woods with her dogs.

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COMMUNITY & BELONGING: TRACING INVISIBLE THREADS

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KEYWORDS: Community; Whole person care; Music

"Do you see the way the trees are bending towards one another?" My grandfather crouches down to my eye level and points toward the edge of the grassy field, where two yellow birches stand against the ripening sky. Their leaves sway in the wind. The trees stand apart. They are separate beings. Yet they lean toward one another, stretching their long branches across the empty space between them. They are shrouded by other trees—mountain ash and maples, great oaks and jack pines that taper into the sky—but they are the only two that are leaning, reaching, as though they are bound by an invisible thread that is pulling them ever closer.

"Is it because they're the same kind?" I ask, eyeing them from the edge of the field. Behind us is my parents' house, and inside it, the people we love. My grandfather lives in Scotland, but he comes to visit us every summer, bringing with him a breadth of knowledge about trees and plants. We cannot know much beyond that moment, crouching by the edge of the field as the evening descends. We cannot know that a few years from now, lightning will strike the tree on the right, leaving a black scar down its trunk, but that after this it will grow even more fully, more feverishly toward its companion. We cannot know that a few years after that, my grandfather will be diagnosed with pancreatic cancer and pass away only weeks later. There is not much to know now, here, except the certainty of the moment and those two leaning trees.

He makes a sound as though he is thinking. A pair of swallows bursts from the tall grass, leaving a shower of old raindrops in their wake as they dip away behind the tree line.

"Perhaps," he says, smiling, "they recognize each other."

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Over two decades later, I am a medical student in Montreal. It is New Year's day and the hospital is quiet. It is the last week of my Psychiatry rotation and I am on the consult service that sees patients in other departments for assessments. As I ride the elevator to the eighth floor, I glance down again at the notes I took during my chart review: *74M suicidal ideation post total knee arthroplasty, possible delirium vs cognitive decline?,* the consult from orthopedic surgery had read. I take a breath, mentally reviewing the criteria for delirium. The winter weeks have been long and dark, and I have found myself slipping into a quiet cycle of studying, clinicals, and sleeping, preserving all my remaining energy for the hospital and patients. Clerkship has been many things—challenging, rewarding, grueling, existential—and although it has affirmed my commitment to medicine, it has been disorienting to watch the world spin by on its axis, to see friends get together in the evenings, to miss family gatherings, and to feel uprooted from the communities that have shaped me.

What communities do I carry within me now? How far away have they grown? How deeply are they buried?

The eighth floor is quiet. He is lying in bed, his head turned away from the door and toward the window, where the snow falls gently and the grey city beyond—its grey buildings that taper into grey sprawl—seems to creak in the cold. I knock on the open door and he turns his head slowly. I introduce myself to him and explain why I am there. He smiles, without breaking eye contact, and looks as though he may cry.

“Thank you for coming to see me,” he whispers.

I approach the bedside. His hair is grey and he looks stricken, as though a great grief has befallen him. As we talk, he answers slowly, sometimes turning to look out the window for long periods of time before responding. He has late-stage rheumatoid arthritis, with pain in his ankles, wrists, fingers, and knees. He describes his pain as ‘unbearable’, even after taking medication. He came to the hospital in November for a knee replacement surgery, and was meant to go home just one or two days later. But he developed complication after complication, and he is still here, nearly two months later.

When I ask him how he is feeling, he tells me he cannot find any feelings at all. When I ask him how long he has been in hospital, he searches my face. He says he cannot remember.

He laughs weakly and shakes his head when I ask if he has any social supports, as though the answer to this question should be obvious.

We do a mini mental status exam together and his hand trembles as he attempts to replicate the shapes on the page. He scores thirty over thirty.

“What is worrying you most at the moment?” I ask, taking the test paper and folding it into my pocket.

He sets the pen down and shrugs his shoulders, raising his eyebrows in a resigned smile. “Oh, lots of things worry me.”

He lifts his left arm toward me and attempts to close his hand into a fist, grimacing as he curls his bent fingers.

“I can barely hold a spoon. I have trouble turning the pages of a book. It hurts all the time. They tried to fix my knee but it’s the hands that are bothering me. I’ll never pick up the guitar again.”

I pause. Sometimes it’s hard to know what to say. “How long have you been playing the guitar?” I ask eventually.

He looks at me and blinks as though I’ve asked him what a guitar is. “Can’t remember a time I didn’t.”

“What kind of music do you play?”

“This and that,” he says, lowering his hand and looking toward the far wall. “Irish, lots of French Canadian, some east coast.” He looks as though he wants to say more, but stops himself. “Nothing special,” he adds.

I don't usually share pieces of myself with patients, but part of me stirs to life and I lean forward, shaking my head in disagreement.

“I love those styles of music”, I say. “I play the fiddle.”

He attempts to sit up and this time when he smiles, his eyes crease. “You do?"

I nod and smile back.

“What are your favorite tunes?” He asks.

And so we exchange our favorite strathspeys and slow airs, reels and jigs. He asks me which variation of the Reel de Montebello I learned— “because there are so many,” he exclaims—and then he tells me about

an album release by a fiddle-guitar duo we both like from the east coast. I take note. We talk about the traditional music community in Montreal, the backroom bars where jams and concerts happen and the small music festivals scattered across southern Ontario where the communities converge.

I have not spoken about music in a long time.

I learned to play the fiddle in my small hometown, where every Saturday members of the community gathered to learn and play together, overflowing in sunlit living rooms or clustered in the old church-turned-community-centre by the river. My parents encouraged my siblings and I to join every week, and soon the unlikely group of musicians—young and old, beginner and seasoned—became a regular community touchstone. It was a place of belonging, of mutual trust, and of unconditional acceptance where one could make mistakes and try new things. As a quiet and reserved youth, I found my voice in my instrument. I made connections with people in our community I would never have encountered otherwise. It was also a road back to our Scottish roots. Our grandfather loved to hear us play, and when we visited him in northern Scotland, my siblings and I often rented instruments from the local shop in Inverness and played together in the evenings.

After high school, I moved away for university, life grew busy, and music fell to the wayside. The years passed and my violin sat in its case beneath my bed. I picked it up only on occasion—to play at my grandfather's funeral, or quietly, alone in my room.

When I moved to Montreal to begin medical school in my mid-twenties, I brought my instrument with me, intent on finding my way back to this place of belonging. I searched Facebook groups and found several weekly trad-music gatherings scattered across the city. I told myself I would go. But I was soon swept up by the demands of my studies, and once again, I could not find space for the music. The community seemed to float further away from me.

The patient is sitting up in bed now, sharing an anecdote about an over-eager fellow guitarist at the local session he used to go to.

"She did *not* respect session etiquette," he said sternly, with a knowing smile. We have stumbled upon a common language, a world with its own rules and traditions, histories and sounds. It is familiar and comforting. It is a community to which we both belong, and to which we will always belong, however deeply buried. It is an invisible thread, offered by a stranger, that is tethered to a part of myself I had forgotten.

After some time, I rise to leave. The snow is still falling outside. The halls are still eerily quiet. He swallows and smiles.

“Thank you for this conversation,” he says softly. “I don’t feel so alone anymore.”

~

I used to think of community as a physical entity—a group of people who come together in the same space with intention and shared dedication to mutual care. An apartment building, a neighborhood, a local cultural organization built around shared interests and goals. Community can be those things, but I think now that community can be more.

Community is something that we can carry within us, across years, cities, even generations. Our communities can become dormant but continue to pulse with a fluttering beat until they are ready to come alive again, to flow out and reach across a room in unexpected ways. They are pieces of identities that we can take and offer to others, so that they may recognize themselves.

As healthcare providers, we too are whole beings with communities that have built and shaped us into who we are: places of worship, artistic endeavors, cultural backgrounds, neighborhoods. In places as foreign and overwhelming as clinics and hospitals, reminders of community can be a grounding force. One day in the emergency room, I heard a fellow medical student slip from French into Tamil as she assessed an elderly woman on a stretcher. She carried out the rest of her assessment in their shared language. Community is a dialect, a memory of home.

Last year, an elderly family member from my father’s side was hospitalized in Montreal. She is from the tiny island of Mauritius, far off in the Indian Ocean. It so happened that my Mauritian friend and classmate was rotating at the same hospital, and when he learned of her illness, he insisted upon visiting her and bringing her special vanilla tea, a staple drink on their home island. He had never met her before, but they sat together one evening speaking in Creole as she sipped the tea he had brought her in a flask. Community is a spice carried by a stranger across oceans.

Another day, I was in urgent care assessing a woman who had come in with a hip fracture. She had fallen on the ice while bringing a pot of borscht soup to her neighbor. The nurse taking her vitals stopped and asked her for her recipe. They had a fleeting but animated conversation about their differing approaches to the recipe, shaped by the differing regions of Ukraine where they grew up. Community is a cooking tradition, a map of one’s ancestry.

We, too, are beings who seek belonging and meaning in the work we do. If our communities are not fixed in space and time, if we can carry them within us and offer them to others in their most vulnerable moments,

then community is a therapeutic aid. We all carry our communities, sometimes without knowing it, and we all have the power to offer and receive these pieces of ourselves as healing tools.

If we have the patience and presence to be curious, the invisible threads are everywhere. It takes only a moment to find them, to trace them. I think about the patient I saw that day on the eighth floor, and I wonder how he is doing now. When I look at my fiddle case these days, peeking out from beneath the bed, it is not so much a reminder of something lost, but a reminder of something warm and familiar that exists beyond its origins.

Like the yellow birches at the edge of the field, we are here, craning into the sky, searching for those we recognize, and reaching our long branches across the space between to find one another amidst the noise. ■

Biographical Note

Rhiannon Ng is a 3rd year medical student at McGill University. She previously studied life sciences and sociology at Queen's University and completed a master's in environmental chemistry at the University of Ottawa. Her essays and poetry can be found in *The Walrus, Best Canadian Poetry 2024, Brick Literary Journal, Grain,* and elsewhere. Her poetry collection *Fire Cider Rain* (Coach House Books, 2022) was shortlisted for the Archibald Lampman Award.

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PROMOUVOIR VIE INTÉRIEURE ET INTERDÉPENDANCE POUR SAVOURER LA VIE

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MOTS CLÉS: Humanisme; Vie intérieure; Interdépendance; Entièreté de la personne

> « Il n'est jamais trop tôt ni trop tard pour travailler à la santé de l'âme. »
>
> — Épicure

L'objectif du présent écrit est de souligner l'importance de cultiver vie intérieure et interdépendance afin de promouvoir empathie, reconnaissance de l'entièreté de la personne et de la communauté.

Mais encore, qu'entend-on nous par « vie intérieure? »

Christophe André, médecin psychiatre français, décrit ainsi la vie intérieure : « c'est un voyage dans le monde des émotions et des sensations, … c'est ce flot de pensées, de souvenirs, de projets, de ressentis émotionnels et corporels, qui se font et se défont en permanence au plus profond de nous. »

Et ce tant au niveau de l'entièreté de l'individu et de la communauté.

À notre époque la vie intérieure est constamment assaillie par des phénomènes de pollutions psychiques, notamment :

- la dispersion digitale aussi nommée folie numérique;
- le matérialisme excessif, et

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- l'égoïsme trop souvent destructeur envers soi-même et autrui.

Dans le même sens, l'être humain et les communautés sont souvent bousculés et leurs démons intérieurs souvent déclenchés, provoquant anxiété, souffrance et brisures de l'entièreté de la personne.

Face à ces maux de la vie des individus et des communautés, et pour mieux prévenir et guérir, Eckhart Tolle pose les trois questions suivantes.

« - Ce dont nous avons besoin, est-ce d'en savoir davantage? »
« - Est-ce que le monde sera sauvé par un surcroît d'information, par des ordinateurs plus rapides? »
« - N'est-ce pas plutôt de sagesse dont l'humanité a le plus grand besoin maintenant? »
Tolle ajoute :
« Mais qu'est-ce que la sagesse, et où peut-on en trouver? La sagesse accompagne la vie intérieure, la capacité d'être calme. Il suffit de regarder et d'écouter. Rien de plus. Le calme, le regard et l'écoute activent en nous l'intelligence non conceptuelle. Laissons la quiétude diriger nos paroles et nos gestes. »

Prévenons les maux de nos vies en accordant avec Christophe André « une attention tranquille et régulière à notre vie intérieure, à cette façon unique d'être qui nous sommes, cette façon unique de traverser le monde. »

Prévenir les maux de nos vies par exemple via l'attention portées aux interdépendances, à l'empathie, la méditation, l'entièreté de la personne.

Vous êtes ici invités à un petit exercice autodirigé de présence attentive, attentionnée : tout d'abord, présence au souffle, puis présence au corps, aux sons, aux pensées, à une simple présence de soi, ici maintenant.

André écrit : la vie intérieure peut n'être qu'un léger bruit de fond présent dans notre esprit, notre cœur, comme un « murmure confus de nos âmes » selon la belle expression du philosophe André Comte-Sponville.

Qui, individu et/ou communauté, sait écouter sa vie intérieure, ses interdépendances pourront les cultiver. Elles pourront devenir de merveilleuses sources d'enseignements d'empathie afin de davantage se connaître, se comprendre et bien conduire individualité, entièreté, humanité.

Christophe André approfondit l'interdépendance :

« Il n'y a pas d'un côté la bonne interdépendance et de l'autre la mauvaise dépendance. De toute façon, nous sommes tous dépendants : de la nourriture, de l'eau, du soleil, de l'amitié, de l'amour… Sans ces dépendances, et sans les personnes qui nous aident à les satisfaire, nous ne serions plus vivants. »

Dépendance s'inscrit dans le cadre plus vaste de l'interdépendance. Notre vie est faite de dépendances réciproques. Nous sommes dépendants de la nature qui elle dépend aussi de nous. Nous percevons fortement ces interdépendances lorsque nous sommes malades, en difficulté. C'est mon cas depuis une année lorsque j'ai appris avoir un cancer. J'ai goûté à des médecins froids mais surtout à des médecins attentionnés, humains. Je vais bien, très bien maintenant. De cette expérience, je vis un sursaut de bonheur et tente d'être plus attentionné comme professeur et comme médecin.

Ne craignons pas d'ouvrir les yeux sur nos dépendances. Aucun de nos succès n'est dû à nous seuls. Parmi les bienfaits de l'interdépendance se trouvent sa contribution à la compréhension que l'estime de soi. « Une estime de soi comprise uniquement via les succès de l'ego nous rend vulnérable à la moindre écorchure individuelle alors que la conscience de l'interdépendance ouvre les yeux sur toutes les présences et bienveillances autour de nous dont le bon usage nous rendra bien plus efficaces et heureux que le fait de ne croire qu'en nous-même. »

Vie intérieure et interdépendance caractérisent ainsi notre humanité et promeuvent la reconnaissance de l'entièreté de la personne, de sa liberté. ■

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Informations Biographiques

Hugues Cormier MD FRCPC MPH DU-MMN a fait ses études médicales et de spécialité en psychiatrie et santé communautaire à l'Université de Sherbrooke (1973-1981). S'en est suivi un Fellowship et un Master of Public Health au Massachusetts General Hospital et à la Harvard University School of Public Health (1981-1983). Il fut professeur adjoint et chercheur-boursier FRSQ aux Département de Médecine sociale et préventive et au Département de psychiatrie au CHUL de l'Université Laval (1983-1993) incluant une année sabbatique au Johns Hopkins School of Advanced International Studies (SAIS) et à la Johns Hopkins School of Public Health (1991-1992).

Professeur agrégé à l'Université de Montréal depuis 1993 au Département de psychiatrie, il a occupé les postes de directeur du Centre de recherche FRSQ de l'Institut universitaire en santé mentale de Montréal (1993-2000), directeur du Département de psychiatrie de la Faculté de médecine de l'Université de Montréal (1998-2000) et, depuis 2019, directeur du Centre Présence en médecine intégrative.

Après une année sabbatique à l'Université McGill en Whole Person Care – Soins de la personne dans son entièreté (2006-2007) avec stages en soins palliatifs au St-Christopher's Hospice de Londres et en psycho-oncologie à l'Hôpital Général Juif, il a complété une Diplôme d'université en Médecine, Méditation, Neurosciences (DU-MMN) à l'Université de Strasbourg (2015-2016) de même que des formations comme qualified Mindfulness teacher au MBSR Teaching Program des universités Oxford and Brown ainsi que plusieurs formations auprès de Christophe André, son mentor depuis 2015.

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THE HUMAN SIDE OF CARE: COMPASSION AS EXPERIENCED BY PATIENTS

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KEYWORDS: Compassion; Patient experience; Qualitative research; Humanistic care; Caregiver–Patient relationship

INTRODUCTION

As healthcare systems increasingly shift toward more humanistic and person-centered models, compassion has emerged as a foundational element of quality care and a defining feature of professional identity among caregivers [1,2]. Conceptualized through varied means, including as a personality trait, ethical stance, and clinical skill, compassion manifests through a range of verbal, non-verbal, and behavioral expressions, shaped by contextual, cultural, and individual factors.

In recent years, empirical research on compassion in healthcare has gained momentum, particularly through qualitative approaches that capture the complexity of how compassion is both conceptualized by professionals and experienced by patients [3]. From the perspective of clinicians, compassion is often framed as a moral obligation and a multidimensional construct encompassing personal attributes (e.g., empathy, sensitivity), relational competencies (e.g., active listening, effective communication) and enabling organizational conditions [4,5]. However, despite its normative and theoretical prominence, compassion remains unevenly integrated into medical and health sciences curricula, clinical practices, professional

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development programs, and health policy frameworks [6]. Many healthcare professionals report feeling inadequately trained to recognize, cultivate, and apply compassion in their daily practice, which raises concerns about the sustainability and authenticity of compassionate care [7].

From the patient's standpoint, compassion is consistently described as a deeply comforting and healing experience, particularly when conveyed through concrete gestures and the acknowledgment of suffering by healthcare providers [8-10]. Compassion has been empirically linked to improved patient satisfaction, reduced emotional distress, and strengthened therapeutic relationships [11,12]. Conversely, although less frequently documented, the absence of compassion can result in significant emotional harm, including feelings of abandonment, humiliation, anger, and a loss of trust in both caregivers and the healthcare system [13,14]. Despite its recognized value, the expectation for compassionate care remains insufficiently met across many healthcare contexts.

The documented gap between caregivers' conceptualizations of compassion and patients lived experiences in clinical settings reveals a critical epistemological and practical tension. While healthcare professionals often articulate compassion in abstract or normative terms, patients tend to evaluate it through embodied interactions that reflect attentiveness, emotional presence, and recognition of suffering. This divergence underscores the need to study compassion not only as a theoretical construct or professional competency, but also as a relational and experiential phenomenon situated within specific interpersonal and institutional contexts.

Previous research has documented patients' and families' experiences of compassion in ways that remain partial and fragmented. Durkin (2018) synthesized qualitative studies to describe compassion as a professional virtue expressed through behaviors such as presence and individualized care, but this research relied largely on secondary interpretations and lacked direct patient voices [15]. Bramley & Matiti (2014) captured emotional impacts through narratives of nursing care, emphasizing the importance of gestures and other forms of communication, yet framed compassion as an individual attribute [16]. An ethno-specific study explored perceptions among South Asian patients, linking compassion to a culturally adapted behavior and respect for beliefs [17].

Across these studies, compassion was often conceptualized cognitively—as a skill or culturally adapted behavior—while its emotional dimension was underexplored or treated in isolation. Further, the relationship between healthcare professionals' behaviors, perceptions of compassion, and the emotional experiences of patients and their relatives remains underexplored, underscoring the need for studies based on patient and family narratives.

Documenting the lived experiences of patients and their families—both in terms of how compassion is cognitively described in clinical settings and how it is emotionally felt, interpreted, and embodied—is essential for advancing a more comprehensive understanding of relational dynamics in care. Such documentation helps identify conditions that foster or hinder compassionate interactions, while also illuminating areas of rupture, unmet expectations, and opportunities for improvement. Patients and families possess unique experiential knowledge that can enrich clinical practice and pedagogical frameworks by offering insights often overlooked in normative discourses. Their perspectives serve as a critical counterpoint to institutional narratives, anchoring compassion in the realities of care and contributing to the development of more responsive, ethically grounded, and human-centered healthcare systems.

This study aims to deepen the understanding of compassion in healthcare based on narratives from patients and families. More specifically, it seeks to document how the behaviors and attitudes of healthcare professionals either align with or diverge from experiences of compassion, and to identify the emotions experienced in response to these interactions from the patients' perspective.

METHODOLOGY

This study is based on an interpretive descriptive qualitative design, grounded in a constructivist epistemology as proposed by Thorne [18]. This approach allowed the authors to capture the complexity of the phenomenon under study through the subjective narratives of patients, emphasizing the diversity of experiences and meanings attributed to compassion.

Recruitment and Data Collection

A non-probabilistic convenience sampling method was used to form the focus group discussions (FGDs). Recruitment was conducted via an invitation letter detailing the study's objectives and participation modalities. The letters were sent by the Human Simulation and Citizen Participation Program (PSHPC) and the Users' Committee of the Integrated University Health and Social Services Centre of Estrie. Semi-structured interviews were conducted in person and co-facilitated by the principal investigator and a patient partner, who was also designated as a co-researcher in this project. An interview guide was developed following Kallio and collaborators framework, which consisted primarily of open-ended questions with optional probes (see Appendix 1). Through their use of varied communication and facilitation techniques—such as active listening, reformulation, and probing questions—the facilitators not only supported participants in expressing nuanced reflections beyond the original scope of inquiry, but also enabled a deeper exploration of the contextual elements shaping their experiences.

The guide supported consistent yet flexible data collection and facilitated the emergence of rich, experience-based findings. A reflexive journal was also kept by researchers throughout the research

process to document analytical insights, decision-making rationales, and reflections as a complementary source of transparency to enhance the study's methodological rigor [19-20].

DATA ANALYSIS

This process was conducted iteratively and concurrently with data collection. Audio recordings were fully transcribed and subjected to a rigorous inductive thematic analysis, combining a vertical approach (in-depth analysis of each FGD transcript) and a horizontal approach (grouping of emerging themes) [21]. This dual reading enabled the identification of manifestations and lived experiences of compassion, both in its presence and absence. *Manifestations* refer to the observable expressions of compassion—or its lack—through, for instance, behaviors, attitudes, or interactions displayed by healthcare providers. In contrast, *lived experiences* encompass participants' subjective and internal responses, including how these manifestations were felt, interpreted, and integrated into their personal care trajectory.

An initial level of co-analysis was carried out by the principal investigator (DG) and the co-researcher (MH-L), resulting in summary syntheses of lived experiences. These were electronically sent to participants for validation and feedback on the collective interpretation. Participants were invited to review a synthesized summary of the analysis and indicate whether it accurately reflected their contributions. They could either confirm the synthesis, propose modifications, or request a follow-up discussion. Overall, participants confirmed that the analysis produced by the research team accurately reflected past discussions. No participant proposed additional changes or deletions, and no substantive modifications were requested. Consequently, their feedback reinforced the study's findings. A thematic analysis, assisted by NVivo software, was subsequently conducted by the research assistant (GL). The active involvement of the patient-partner throughout the study—especially in co-facilitating focus groups and analyzing data—enhanced the credibility of the approach by offering a unique, informed perspective. Participant validation through summary feedback and researcher triangulation, supported by debriefing sessions, enhanced the accuracy of interpretations, reflexivity, and methodological transparency, while contributing to the reduction of bias.

ETHICAL CONSIDERATIONS

The project received ethical approval from the Research Ethics Committee of the CIUSSS de l'Estrie–CHUS. All participants signed informed consent before data collection. To safeguard participants' emotional well-being, measures were put in place, including access to psychological support services. Confidentiality of the data was rigorously maintained through the anonymization of personal information. All documents, transcribed data, and audio recordings were securely stored, with access restricted through dual authentication protocols.

RESULTS

The findings of this interpretive qualitative study shed light on the multifaceted nature of compassion as experienced within healthcare settings. Through the narratives collected during two focus group discussions, a diversity of profiles and experiences revealed rich relational dynamics—sometimes marked by the transformative presence of compassion, and other times by its painful absence. This section first presents the participants' profiles, then explores the concrete manifestations of compassion in caregiver–patient interactions, and finally examines the emotional and relational impacts of its absence. The narratives highlight profound issues of recognition, dignity, and humanization at the heart of the care relationship.

Participant Profiles

The study was conducted with twelve participants divided into two focus group sessions, lasting 1 hour and 52 minutes and 1 hour and 38 minutes respectively. The composition of the groups reflects a notable diversity in terms of gender, age, educational background, and socio-professional status, allowing for a rich array of perspectives on the experience of compassion in healthcare. Gender distribution was balanced, with six women and six men. Regarding age, most participants (64%) were aged 55 and older, suggesting a broader experience with healthcare, both as patients and caregivers. Age ranges spanned from 25 to over 65 years, ensuring generational diversity in the narratives.

In terms of education, participants had varied levels ranging from high school diplomas to master's degrees, with a predominance of post-secondary education (college and university). This diversity enriched the interpretations and expectations regarding compassionate practices. Participants' main occupations were also heterogeneous: some participants were active in the workforce, others were retired, caregivers, volunteers, students, or on medical leave. Several held multiple roles, such as retired and caregiver or student and worker, reflecting the complexity of life trajectories and contexts in which compassion is experienced.

MANIFESTATIONS AND EXPERIENCES

The findings of this interpretive qualitative study offer a rich and nuanced understanding of compassion in healthcare, as lived and narrated by patients and their caregivers. Through the analysis of lived stories collected during focus group discussions, relational dynamics marked by the presence or absence of compassion emerge, revealing deep and sometimes contrasting emotional effects.

Presence of Compassion: A Transformative Relational Experience

Participants from both focus groups converge on a definition of compassion as an authentic human presence, grounded in listening, recognition, and engagement. Compassion is described as a relational, communicational, and human practice that can profoundly transform the care experience.

Compassion first manifests in the quality of the relationship between caregiver and patient. It is described as emotional and physical proximity, expressed through simple yet meaningful gestures: sitting at the same level as the patient, holding their hand, greeting warmly, taking time to explain, validating understanding, or simply being present. One participant shared, "*The doctor stood up and came to sit next to me. That made all the difference*" (FG#1). This proximity helps break the implicit hierarchy between caregiver and patient, establishing a human-to-human connection. When these behaviors are carried by a respectful and benevolent attitude, they generate feelings of safety, dignity, and trust.

Participants also emphasized that empathetic listening is at the heart of the compassionate experience. It involves paying attention to the person's story, going beyond technical evaluation, and showing genuine interest and presence. As one participant reflected, "*sometimes not speaking at all, just being there*" (FG#2). They stressed the need to be seen and understood in their uniqueness, to move beyond labels and diagnoses and recognize the human being in front of them: "*She didn't see the addict, but the little girl who was suffering*," said one participant. This recognition helps restore dignity and strengthen humanity.

Considering the person's needs, goals, and pace is also perceived as a powerful marker of compassion. This attitude allows the patient to feel welcomed, respected, and valued, as reflected by this study's participants. When caregivers acknowledge the patient's strengths, experiential knowledge, and vulnerability, they help establish a therapeutic relationship based on co-construction and reciprocity: "*He took the time to understand my situation, my abilities, and limitations*" (FG#2). Compassionate communication also involves word choice and tone: "*Even humor, when appropriate, can make a care experience more positive*" (FG#1).

When a caregiver acknowledges their limits, even as a specialist, they do not relinquish competence but humanize the relationship. This transparency creates a space of trust where the patient feels respected, heard, and considered a partner in the care process. Patients' stories reveal that this posture of humility breaks the implicit hierarchy; "*Admitting you don't know, and saying it*" (FG#2), opens the way for a relationship where medical and experiential knowledge coexist and complement each other. Admitting limits, uncertainties, or even emotions—"*She temporarily stepped out of her medical role and entered the human realm; she even cried with us*" (FG#1)—strengthens the caregiver's credibility and validates the patient's experience, demonstrating that "*beyond medical science, there is humanity*" (FG#1). This posture also reduces pressure on the patient, who no longer has to conform to an idealized image of the omniscient caregiver. It allows the healthcare professional to shed the burden of infallibility and open a more sincere, respectful, and human dialogue.

Participants also highlighted the importance of support throughout their experience; "*I'm with you on this journey*," said a doctor to a cancer patient to illustrate support. Being guided, assisted with procedures, or

simply being visited after an intervention are gestures that reflect care for the illness without infantilizing the person. This distinction between managing the medical condition and respecting the patient's autonomy is central to a form of compassion that fosters empowerment.

Absence of Compassion: An Experience of Rupture and Suffering

Participants' narratives reveal that the absence of compassion leads to care experiences marked by loneliness, anger, and a sense of abandonment. Behaviors perceived as cold, distant, or mechanical are experienced as forms of dehumanization. Deliberate disregard for the patient's words, refusal to consult or acknowledge their expertise, and stigmatizing attitudes contribute to a one-sided view of the situation that denies the person's wholeness. Compassion is not limited to the caregiver–patient relationship; it also includes relatives, whose roles are often ignored or minimized. "*I was informed of my husband's transfer by voicemail* […] *they didn't speak to me, didn't consult me*" (FG#1), said one participant, feeling excluded from administrative decisions with major consequences for the family.

Participants also described situations where judgment based on age, disability, or mental health diagnosis led to decisions made without their consent, and even to humiliating remarks: "*As soon as he heard 'addiction,' the judgment came… and then you lost all your rights*" (FG#2). Comments like "*Aren't you tired of being in the hospital?*", often delivered in a harsh or condescending tone, are perceived as a negation of the person and experienced as verbal violence, often generating humiliation and anger. According to participants, non-verbal cues can also be hurtful: "*She threw the CD on her desk*," (FG#1), conveying contempt or indifference. These experiences were described as traumatic, undermining trust in caregivers and the healthcare system.

All participants agreed that in a care context, the caregiver's words hold strong symbolic power. When used to belittle, infantilize, or demoralize, they can deeply affect the patient: "*The lack of compassion… it can really degrade you*" (FG#1). Testimonies from the focus groups show that such discourse is experienced as a form of violence that weakens the therapeutic relationship and compromises trust: "*It's like I didn't exist*" (FG#1). This type of communication harms the patient's self-esteem and may discourage them from expressing their needs or concerns. The impact is even greater when such remarks are made during vulnerable moments, such as a difficult diagnosis, loss of autonomy, or prolonged hospitalization. The patient may feel devalued, isolated, even abandoned by those meant to support them: "*I couldn't see the light at the end of the tunnel*," "*I felt degraded, subhuman*." The absence of compassion thus has profound emotional and psychological repercussions that can even compromise treatment adherence.

Several participants recognized that systemic barriers—such as workload, time constraints, and administrative pressures—can hinder the expression of compassion without necessarily implying malicious intent. As one participant noted, *"We have to put ourselves in the caregivers' shoes too."* While they

expressed empathy toward the realities faced by caregivers, they also stressed that the absence of ill intent should not minimize the significance or impact of these experiences.

One participant remarked, *"The patient has a job to do. It must tap into my motivation and engagement"* (FG#2), offering a perspective that positions the patient as an active and empowered contributor to the care relationship. This view contrasts with traditional representations of the patient as a passive recipient of compassion. Instead, it affirms the patient's role in fostering a relational dynamic grounded in mutual engagement, motivation, and collaboration. As another participant shared, *"We talk differently when we feel we're with someone equal on a human level"* (FG#2).

SUMMARY OF KEY FINDINGS

Table 1 presents a comparative overview of the manifestations and emotional impacts of compassion in healthcare, as experienced by patients and caregivers. The table highlights key dimensions such as relational gestures, communication style, emotional engagement, and systemic awareness, offering a clear contrast between compassionate and non-compassionate care.

Table 1. Summary of Key Findings

Dimension	Presence of Compassion	Absence of Compassion
Relational Gestures	Sitting at eye level, holding hands, warm greetings, being physically present	Cold, distant, mechanical behaviors; lack of eye contact; absence of physical proximity
Communication Style	Respectful tone, empathetic listening, validating understanding, appropriate humor	Harsh or condescending remarks, verbal violence, infantilizing or moralizing language
Recognition of the Person	Seeing the patient beyond diagnosis (e.g., recognizing suffering, uniqueness)	Stigmatizing attitudes, judgment based on age, disability, or mental health; ignoring patient's voice
Emotional Engagement	Caregivers showing vulnerability, admitting limits, expressing emotions (e.g., crying with patients)	Emotional detachment; refusal to acknowledge psychological suffering or emotional needs

Support and Accompaniment	Statements of solidarity ("I'm with you on this journey"), follow-up visits, assistance with procedures	Lack of follow-up, exclusion from decisions (e.g., family not consulted), feelings of abandonment
Therapeutic Relationship	Co-construction of care, mutual respect, shared decision-making	One-sided decisions, lack of collaboration, undermining patient autonomy
Impact on Patient	Feelings of safety, dignity, trust, empowerment, motivation	Feelings of humiliation, anger, loneliness, degradation, loss of trust, emotional trauma
Systemic Awareness	Recognition of caregiver constraints; patients expressing empathy toward caregivers	Systemic barriers (e.g., time pressure, workload) leading to professional burnout or neglect
Symbolic Power of Words	Words used to comfort, validate, and humanize	Words used to belittle, exclude, or dehumanize; experienced as symbolic violence

DISCUSSION

The results of this qualitative study illustrate that compassion, when present, transforms care into a human encounter. It is grounded in concrete behaviors, sincere recognition, and respectful communication. Its absence, on the other hand, can intensify suffering and undermine the therapeutic relationship. These narratives call for a transformation of practices based on listening, education, and the valorization of patient knowledge. Participants' statements echo the work of Baguley et al. (2022) and Barker et al. (2023) [10-12], which shows that patients associate compassion with simple yet meaningful gestures: a look, a smile, a gentle voice, an open posture. These elements are also present in the findings, where patients emphasize the importance of eye contact, warm tone, and physical and relational proximity. Conversely, harsh or demeaning remarks cause deep wounds. These experiences confirm that compassion is not limited to intention; it is expressed through language, non-verbal cues, and attentiveness to the other [3, 13].

Recognizing the expertise of patients and caregivers, along with the co-construction of care, aligns with the patient partnership movement [22, 23]. Participants appreciated professionals who considered their goals, experiential knowledge, and lived experiences—an approach consistent with the principles of the Montreal Model and its call for ethical transformation in practice [24]. The patient-partner's active involvement throughout the study positively shaped the co-facilitation dynamic, fostering trust and openness among

participants. The well-documented benefits of compassion—such as increased trust, engagement, and patient empowerment—further support this approach [9, 10, 25, 26].

Despite these convergences, some results highlight concerning gaps between caregivers' practices and patients' perceptions. Several participants reported experiences lacking compassion, marked by cold attitudes, stigmatizing remarks, or exclusionary behaviors. These experiences align with Eriksen et al, who analyzed formal patient complaints and identified dehumanizing dynamics in care settings [8]. A significant tension lies in the non-recognition of psychological suffering and emotional vulnerability. While literature emphasizes the importance of considering the person holistically [5, 25], some stories reveal an exclusive focus on physical symptoms at the expense of listening to subjective experience.

Moreover, this study makes an original contribution to the literature on compassion in healthcare by revealing a rarely explored dynamic: patients' recognition of caregivers' suffering. This reflective capacity of patients deserves greater recognition in professional training, healthcare policies, and organizational models. Recognizing systemic constraints, such as workload and organizational priorities focused on performance rather than relationships [28], can lead to a form of professional dissonance where caregivers, despite being driven by humanistic values, struggle to embody compassion in their daily work. These findings also invite us to recognize compassion as a shared responsibility, involving an active posture from the patient and an openness from the caregiver to co-construction. This perspective aligns with the work of Naik and Cheu et al., [30,31].

By giving voice to those directly affected, this research sheds light on the clinical environments and the levers for transforming practices toward a form of compassion that is embodied, contextualized, and shared. These findings call for a revaluation of relational competencies in the training and assessment of healthcare professionals. They confirm the importance of integrating patients' experiential knowledge into both clinical and educational practices [27] and of promoting an organizational culture grounded in humanism [28].

This study presents notable methodological strengths, including the use of focus groups to generate rich, contextualized narratives and the integration of a patient-partner, which enhances the validity of the findings and supports a co-constructed understanding of relational and communicational dynamics in care. However, certain limitations must be acknowledged. The convenience sampling—composed of participants already sensitized to compassion and partnership—may introduce bias, while the small, region-specific sample (n = 12) limits transferability to other contexts. The analysis, grounded in subjective perceptions, offers valuable insight into lived experiences but cannot establish causal links with clinical outcomes. Finally, the absence of healthcare professionals' perspectives restrains triangulation and may introduce interpretive bias.

CONCLUSION

This qualitative study sheds light on the complexity and depth of compassion as experienced by patients in healthcare settings. Far from being merely a professional attribute or technical skill, compassion emerges as an authentic human encounter rooted in listening, recognition, and reciprocity. The collected narratives show that compassion transforms care into a relationship, while its absence leads to emotional and relational ruptures with potentially lasting consequences. By revealing the impact of simple gestures, kind words, and respectful attitudes, this research confirms the importance of revaluing relational competencies in clinical practice and health education. It also offers a conceptual advancement by highlighting the active role of the patient in co-constructing compassion and recognizing their ability to perceive and respond to the caregiver's vulnerability.

These findings call for an ethical and organizational transformation of healthcare environments, where compassion is no longer an abstract ideal, but a shared, embodied practice supported by a humanistic institutional culture. By integrating patients' experiential knowledge into care models and training programs, we can build a more just, sensitive, and truly person-centered healthcare system. ■

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APPENDIX 1: INTERVIEW GUIDE

Narratives of experiences in the presence of compassion

Cognitive dimension: You are invited to recall a situation in a care context during which a caregiver demonstrated compassion toward you or toward one of your loved ones. Take a few minutes to remember this person and this situation.

> ➤ *"Who was this person, and what was his / her role in your care or in the care of your loved one? What sets this individual apart? In concrete terms, how did they express compassion? In what care context did this occur? Were there any contextual factors—such as concerns, values, or cultural aspects—that influenced your experience of compassion?"*

Affective dimension: You are now invited to describe your lived experience and your feelings during this compassionate encounter with this person.

> ➤ *How did you experience this compassionate interaction? What emotions did you feel? What impact did this experience have on you? In what ways did this compassionate encounter influence your care?*

Narratives of compassion-deficient care experiences

Cognitive dimension: You are invited to recall a situation in which you feel that a caregiver lacked compassion toward you or toward one of your loved ones. Take a few minutes to remember this situation and this person.

> ➤ *Who was this person, and what was his / her role in your care or in the care of your loved one? Which attitudes or behaviors, from your perspective, indicated a lack of compassion? What contextual factors might have influenced this person's attitude?*

Affective dimension: You are now invited to describe your lived experience and your feelings during this encounter with this person.

> ➤ *How did you experience this lack of compassion? What emotions did you feel? What impact did this experience have on you? In what ways did this lack of compassion influence your care episode?*