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EDITORIAL

SOME REFLECTIONS ON WHOLE PERSON RESEARCH

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KEYWORDS: Pain, Suffering, Whole person research

I have been thinking lately about what it means to approach my research from a whole person perspective. To be honest, I don't really know. And, yet, I think I've been slowly and inadvertently cultivating this approach since I first started as a researcher, some 20 years ago. My sense is that it involves simultaneously comparing and honing two contrasting images. One is of the phenomenon itself. For me, this is people who are experiencing pain and suffering, but let's imagine for a moment this as the sun. It's hard to look at (and thus study) the sun directly, so a second, simplified image is needed. This is the *image* of the phenomenon that is generated through our research methodologies. This second image is always a distortion of the first. We might use a prism to help us study sunlight, but it can only provide narrow insight into the actual qualities of the sun. Extending this metaphor, I like to imagine my research tools as *a crooked finger pointing at the moon*. My job, then, is to try to straighten and reorient this finger so that it leads us toward the actual *source* of light we want to understand (rather than just directing us to the closest surface lit by its reflection).

Being able to see the distortion within the research-generated image requires an immersion in the phenomenon of interest. I want to cultivate a deep, personal connection with the phenomenon that I'm studying. My hope is to generate a set of memories, feelings or imagined feelings that can be conjured when critical reflection is needed. Einstein famously imagined himself riding on a beam of light, which, in turn, helped him see how the research tools of his time needed reorientation. For me, this often involves more modest means, such as self-reflection and careful observation of others. *What exactly was I feeling when I broke my arm? Is my infant daughter suffering when she cries? What does my patient mean when they say they were blinded by the pain?* In recent years, I've also started partnering with people living with pain in this process. Being able to integrate their first-hand reflections and observations within our research process brings us closer to our proverbial sun and dramatically improves the resolution with which we can examine the distortions created by our research methods.

Working to correct these distortions is an inherently messy process. Science loves parsimony. But when applied to the human condition, this can mean cutting clutter that often turns out to be essential. Tim Harford's book, *Messy*, provides a valuable compendium of historical examples that either embrace or shun messiness.[1] Harford uses these to effectively shine a bright light on the dark side of Occam's razor – essentially, bad things happen when we fail to embrace the messiness of the phenomenon that we're trying to understand. Consider the nature of pain for a moment. Unlike sight, sound and other human senses, pain is a jumbled mix of emotion and sensation. Pain's emotionality makes us jump to its attention – an inner drill sergeant that likely facilitated the survival of our species. Pain is also a function of who we are – our unique mix of genetics, learning history and present context make it so that we potentially each experience and interpret pain differently. Now, contrast this complexity with our most common clinical and research metric of the pain experience – a simple 0 to 10 scale of pain intensity. Intensity is certainly an important quality of pain, but it is still just one small part of this complex and subjective experience.

While not included in Harford's book, the failed *Pain as a Fifth Vital Sign* campaign provides a prime example of the perils of ignoring messiness within our research and practice.[2] The campaign, born in the mid 90's, was simple – let's try to improve pain management by integrating its assessment into the routine clinical evaluation of heart rate, blood pressure, temperature and respiratory rate. The pain intensity scale was advanced as the sole tool for administering this assessment. The problem, however, is that this scale fails to capture the meaning and context that shape patients' experiences of pain – 5 on 10 pain during labour and delivery can be quite a different experience from 5 on 10 pain during treatment for terminal cancer. The longer-term legacy of anchoring this international campaign to this overly simplistic assessment tool is, in part, today's opioid epidemic.[2]

Opioids turned out to be an excellent way of reducing scores on the pain intensity scale. But what these scores mean to the patient versus the prescribing physician might only be tangentially related. When the physician asks about pain intensity, the patient may also be communicating all of the suffering and hardship that they're currently experiencing – particularly if this number is their only avenue for conveying this distress, as it commonly was during the Fifth Vital Sign campaign. Patients' 11 on 10 pain scores are likely more often trying to convey suffering than they are trying to quantify their experience. Unfortunately, opioids also provide an escape – that's all too brief, and far too costly – for this unaddressed suffering. In retrospect, this now abandoned "evidence-based" campaign to streamline and standardize pain assessment primed clinicians to ignore and mismanage the suffering that patients too often experience when in pain and turned out to be a tragically common pathway for addiction, overdose and death.

So, what is the whole person approach to research in this context? Well, for me, it involved a shift to using research methods that could engage with more of the inherent murkiness that characterizes human experiences of pain and suffering. Rather than trying to assign a number to everything I was studying, I started using qualitative methodologies that empowered participants to use their own words, via long-form interviews, to describe their experiences. I was blown away by what we found – an uncharted sea of data, just below the more superficial numbers that I had been focusing on. These qualitative interviews helped bring the whole person into better focus and allowed our team to develop a new richness for understanding the nature of pain-related suffering – findings that we hope will help inform more holistic approaches to its clinical assessment and management. Partnering with people living with pain in this process certainly added further complexity (or "messiness"), but also proved essential in helping us hone our interview approaches and interpret our findings. I was also surprised to learn how much I enjoyed running these interviews. It brought me closer yet to the lived experiences that I was trying to understand and made use of inter-personal communication skills that I had yet to fully engage within my research – having *more of myself* engaged in my work has been a reliable indicator of whether I'm headed to a place where I want to go.

And, yet, I don't want to advocate for a one-size-fits-all approach to whole person research. While qualitative methods are proving incredibly valuable at this present moment, I still don't see myself as a qualitative researcher, per se. My hunch is that less dogmatic entrenchment within our favourite research methods would better enable us to stick our heads up and build much needed connections to other research silos. In my work, I'm keen to explore how we might be able to link the qualitative themes on suffering that we're discovering to some of the more established brain-related changes that my quantitatively oriented field has focused on in recent decades. There's something appealing to me about exploring how this type of objective data might be connected to some of the messiest, most subjective aspects of pain. I also believe that fitting these types of disparate pieces together also brings us closer to creating a more accurate image from the research jigsaw that we're all trying to solve.

The more I reflect on this approach, the more I appreciate the unique role that practicing clinicians play within health research. Clinical practice is about *as close to the sun* as we can get, and it is an inherently messy process. We're confronted daily with the raw wholeness that is the person seeking help for their health. This vantage point offers unique insight into how our best evidence either serves or fails the patient in need. The first-person pieces in this issue capture this dynamic perspective beautifully. This issue also includes our first piece in the Journal's new *Wisdom in Practice* stream. The objective of this stream is to provide a forum for clinicians to share how they've wrestled with aspects of patient care that don't fit neatly within evidence-based practice guidelines. The intention is to serve as an accessible bridge between our first-person narrative pieces and the more methods-focused research that is included in both this issue and the supplement to this issue; the supplement provides the abstracts for the work that was presented in the recent 5th Congress on Whole Person Care. My hope is that this Journal can help foster some meaningful community around this whole person research process – welcoming folks that might not see themselves as researchers into the scholarly art of trying to discern what shapes the orbit of our professional worlds.■

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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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DEATH AND THE SHOVEL LADY

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Keywords: Life, Death, Values in medical practice

Cycling to work, on a good day I can sustain this illusion - that nothing changes. Everything is as it has always been.

It's autumn now, the mornings are dark again and the leaves are turning. The first of the season's cold, today I have to work hard to stay warm. My commute takes me twenty minutes. It sets me up for the morning, and helps me dissipate the accumulated mental garbage at the day's end. There's a light fog hanging over the loch, and colonies of water birds have gathered in the grey - herons, perched and unmoving, sinister in their long grey coats; a phalanx of three mallards makes a finger, three winged bones pointing toward the sky.

There's meaning in all this, I think. The squat form the church tower makes, rising above the mist; the slate grey of the water merging with the sky; the mad reds and the yellows of the spiralling leaves. This view, seen from just this angle, it hasn't changed, for hundreds and hundreds of years.

The Shovel Lady has her house beside the church, I can pass it on my route, if I choose. Someone's ancestors were sold that land by the church a long time since, and built a cottage on the plot, with a garden stretching down to the water's edge. The Shovel Lady and her husband acquired this place a life - time ago, and had lived there since - content enough together for sixty years, and then she alone, for ten.

I call her the Shovel Lady after a joke that she made to me, just before her husband died.
The last few months of his life had not been good. Even at his best a dithering old man, rather powerless in the face of his wife's assertions, latterly he had withered, brain shredded - too much tobacco, alcohol,

atheroma, a life lived too much in deference, and now he was disappearing altogether. He had been a company's accountant during his working life, and in his retirement had painted water colours. The walls of his studio were hung with his work: the church, the apple trees in his garden, the colonies of water birds, the endless weather, meticulously rendered. I had been visiting him on his death bed. He had aspiration pneumonia, he had wanted to stay at home, was dying well on a syringe driver, at peace. I had ministered to him, he and I alone in his room, in a kind of silent intimacy. She had stayed in the garden. She had left us to it. Considerate of his privacy perhaps, though oddly detached. I met her as I was leaving. She had a plastic bucket of windfalls in one hand, a shovel in the other. She was slightly out of breath, having hurried from the bottom of the garden, to catch me before I left. I noticed her ankles were swollen, I noticed how she pursed her lips a little as she exhaled.
'Doctor,' she said, 'when I get like that, please just whack me over the head with this shovel, and bury me under my apple trees…'
I laughed with her. I have always liked Shovel Lady.
'Can't do that…'
'Please, please, don't let me get old.'
There was tenderness in her voice, and fear. As if her husband was already a memory. As if she were adjusting already to the fear of her solitude.

And now, look, ten years on, it's her turn.

She is very much in my mind today. Last week, she stopped eating. Then she took to her bed. At first she accepted sips of fluid from her grand-daughter, then she stopped. I thought, quite arbitrarily, *now, at last, it's time*. I started her on a syringe driver, just before the weekend. Always a mistake. Sometimes, listening to specialists in palliative care, they make it sound… easy. It's never easy.

I turn off the cycle path and into the complex where the doctors' offices are. This illusion of un-changing ancientness is rapidly dispelled - I change into scrubs, fire up my computers, field a dozen messages from reception staff, the nursing staff, the pharmacy staff, my anxious trainee. There is a message for me from the out-of-hours service. They look after our patients when the lights here are out.
<Mary Grey (that's Shovel Lady's real name) has had a bad night - agitated and crying out, the family are angry and want something to be done…>

I breathe deeply. Too many medical interactions are framed in this antagonistic way. You haven't done enough. You NEVER do enough. But this is the nature of my calling.
Really, there is nothing to be done. Yet nothing I do will ever be enough.
Six months previous, Shovel Lady had had a short hospital admission with acute on chronic renal failure, and pulmonary oedema. Partly my fault, if fault is the right word. Against my better judgement, I had been managing her chronic all-over-body pain, her chronic breathlessness, with low doses of mild opiates - which had, in the way of things, become high doses of strong opiates. Her gardening days were long behind her.

‘If we go this route,’ I had said, ‘we can surely help you with your pain, and your breathlessness. But the effect of the drugs will almost certainly shorten your life…’
‘I’m ninety-two…’ She had said, pointedly.
‘All the same…’
‘Bring it on!’

But Death never comes on time. Always early, always late, never on time, always a bad guest. So, Mary was admitted against her will to the hospital, water logged and breathless. She was dried out, her opiates reduced, sent home again, once more in too much pain to move.
I visited her, regularly.
‘You promised me I would never get old!’
‘I made you no such promise!’
‘You promised me that you would whack me over the head with a shovel and bury me in the garden under the apple trees!’
‘I made you no such promise!’
We had re-started her opiates, titrated up the dose, waiting again, endlessly, it seemed, for Death.
Her daughter was with us. Her daughter is appalled. Her daughter is a meticulous person, a little given to sarcasm, ill-used I think, by a life-time of exposure to her mother’s blunt manner. Her daughter calls me regularly, keen that her mother be admitted to a facility for the elderly where she can be ‘properly cared for’. When I try to explain that this would fly in the face of everything that her mother has ever asked of me, it doesn’t wash. And I understand the daughter’s point of view. I couldn’t live my life as she does - waiting always for the news of the fall at home, or the terrible burn, the panicked voice of the carer, the pre-dawn call announcing her mother’s death.
‘Stop fussing then! Just whack me over the head with a shovel!’
Mary cackles with laughter. As if her defiance, the engulfing blackness of her humour, is all that remains.

*

We value Death differently, when we think of her at all. Her meaning for us changes, from day to day, from person to person. But it is she that lends the colour and glimmer to the arc of our brief lives.

I’m minded to think of a rainbow. A shimmering fractal. The arc of its colour. Suspended, majestic above the earth, rooted at two points on the ground, which can be clearly seen, yet are wholly imagined. Its form and nature contingent on the location and presence of a witness. Its glory, on its transience.
Now imagine, however briefly, this rainbow becoming aware of itself.

*

This week, we - our team - contribute to the care of a child, who is coming to his end, far too soon. The child has a rare neurodegenerative disease, that became apparent in the first few weeks of his life. He learned to latch, then to smile, then to laugh, to follow his mother and his father with his eyes-- but then this learning stopped altogether, and he regressed. He is eighteen months old now. He is tube fed. He is on high doses of sedatives to prevent the fits that distress his parents, who have sat in vigil at his cot side, for week upon long week. The child has no awareness.

His parents understand that he must die - in some sense - we sense - they both long for it, but dread it. They are lawyers, both, he on a track towards seniority, she, who now knows, her career stalled by that un-looked for tragedy.

Our team have nothing to do with the complex technical aspects of the child's care. Our duty is the simplest. When he dies, we must be there, to visit him, to certify that he is deceased, to register a death certificate, that is accurate - the briefest account of a life, and its end. It's an administrative task, no more. The child's life means nothing to the child - he doesn't have that capacity. His life, and its end, means everything - it is the whole world - to the parents. Our duty, trivial though it may be, weighs heavily on us, on our team. We make up a rota so that we may be ready to respond, with kindness and compassion, in an instant. We talk about this in hushed voices.

Then Mr. Prassad comes to see me, on time at 2PM about his erectile dysfunction. Mr. P, who runs a grimy grocer's shop on the other side of the tracks, is seventy-five years old. He almost died of COVID. Death had stooped, early in the pandemic, carried him off in her scimitar talons, her great beating wings carrying his weight effortlessly - but then she let him fall. Who knows why? Death in her bird avatar can be capricious.

He was on an intensive care unit, for several months, on a ventilator. Bang in the middle of that demographic least likely to survive - overweight, diabetic, south Asian, poor - but he did - he struggled through.

Our health service in the UK has been damaged, probably beyond repair, by greed, neglect and the voracious needs of capital - but it has a core, a resilience in its people, and sometimes, quite unpredictably, it plays a blinder. Mr. Prassad was discharged home from hospital, still on oxygen. A 24 hour team of nurses and carers deployed to keep him breathing. Mr. Prassad struggles on, for months. There is talk amongst us, of futility, wringing of hands and some sombre shaking of heads, and an attempt is made to talk to his family about the end of life, the inevitability of his death, the importance of mitigating of suffering, and they tell us, with the greatest of kindness and generosity of spirit, to fuck right off. They were so right; we were so wrong. So often it is like that.

Mr. Prassad has lost weight. His diabetes has remitted. Despite the devastation of his pneumonitis, he is barely breathless. He has returned to his religion - wears a beard now, and more traditional clothes, has a prayer bruise in the centre of his forehead.
'Sex has always mattered greatly to my wife and I.'
He asks me with a twinkle, whether I have heard of a drug called 'viagra'? (I have) And whether it might be safe for someone with his particularly extensive medical history? (I don't know - I suspect that no one knows. It is a matter of judgement, of risk.)

But life demands it. His life, demands it.
Life just surges through.

*

We find ourselves: glistening, transient, things that perceive and feel, bathed in light and colour, startled into being.
Arced between two imagined points of solid ground: our before, our after.
The conditions that permit us - our light, our water, our air - so fragile.
And within that luminous, contested domain, is generated everything. Everything we value is contained.
But the rainbow leaves no trace of itself after it is gone.

My thing, if I have a thing, is this. A modest claim.
We, doctors, healers, of all kind, are trained almost exclusively in a discipline: the science and technologies of the material world. Facts and numbers that explain to us our decaying bodies. Powerful disciplines! Powerful tools! Don't knock them. So very often our presence here depends on this kind of knowledge. But this bright light leaves in shadow the proper, elusive nature of our selves: that glimmering place where we all have our lives. Without consideration of the second, I think the first has no purpose.

I have another thing. A second modest claim.
That it is transience that gives anything value. Everything, everywhere, always has an end. That is why we treasure things. Somehow, we might learn to prize this transience.

Death crops up all the time, in our work. Death is everywhere, universal, omnipresent, the necessary context that gives our lives their meaning, and yet whose necessary existence we ignore - we, the healers, most of all. It's in our nature to deny her.
Death is the portal, death is the spirit guide, death is the point of intersection between these worlds - the shadow world of things, the radiant world of being.

*

I am late again - it will be my last visit to the shovel lady. Her wait is almost ended. It is evening by the time I get there. Almost dark.

I have been detained - a late addition, right at the end of the day. It always seems to happen this way - these kinds of calls. They can seem like distractions, when in fact they are the point of it all.

A young woman has tried to kick down Death's door herself. But found Death not at home. The rope broke the light fitting. She had landed with a thump on her back-side on her bedroom floor. Her flat mate found her there, sat beside a chair, a noose at her feet, awash with tears. The grief. The humiliation.
'Yes, I wanted to die. No, I don't want to die now. No, I can't see any point in going on. No, I won't do anything stupid. Yes, I guess I'll muddle through. I always seem to.'

She looks at me. She's angry - with me, her flat mate, at everyone, except the feckless lover who left her, and came back, left her again, and came back. He is also my patient, as it happens. Talks to me, endlessly, about his gambling, the women who persecute him, his substance issues. I struggle to care.

She has a rope burn on her neck, which she has half concealed with a silk scarf.

I could ask for a psychiatric evaluation. She has had a few. I could arrange for her to be detained in hospital, at least for a few hours, before they send her home again. I could arrange a clinical psychologist, a therapist, a community psychiatric nurse assessment, but none of these services exist now in the desert of compassion that my country has become. Besides, it would all be in the service of a lie. She isn't sick. I could arrange to take out a contract on the boyfriend - that would probably be easiest, and most likely solve the problem.

'What do you need from me?'

'Nothing. To be left alone. Please leave me alone.' She dries her tears.

To my surprise, she thanks me warmly as she leaves.

'I know that you mean well, doctor.'

That morning I had increased the dose of sedative in Shovel Lady's syringe driver, and now, a few hours later, I need to check on her.

Everything is still when I arrive. The snippy daughter says, 'you took your time…!' Her granddaughter shrugs her shoulders at me, saying don't mind her - that's just mum.

I take my place at the bedside - a hospital bed set up in her husband's old studio. I can see the shadows of the apple trees outside the window, the black water of the loch behind.

I reach under the blanket, and take her hand, hoping for a response. This is not the kind of relationship I have ever had with Shovel Lady - but it seems that now it is, because almost imperceptibly, she squeezes back.

Music is playing from a device on a shelf in the corner. Abba. 'Winner Takes It All.' I find myself welling up. Throat tight. Tears. Beyond embarrassing. I had no idea that I cared so much. She's over ninety! For years she has wanted nothing more than to be dead…

I find sometimes that I have almost no defences to music.

'Grandma loved her music. The sadder the better.'

Nothing more to say,
No more ace to play…

Sings Agnetha. What a voice that woman had! I swallow my tears.

'I didn't know that about her.'

I don't think it will be long now. Her skin is pale, a blueish colour around her nose and lips. Her breaths are shallow and I can tell that she is a little dry.

'It's not how she wanted it. She really didn't want this.' Says the granddaughter, wistful.

‘No. I know.’
‘It’s not the shovel, is it, eh?’
‘No. She mentioned the shovel thing to you as well?’
‘All the time. It was her go-to conversational topic. She’s been wanting gone for years.’
‘I know.’
‘But I suppose we’ve all done our best…’
‘I guess we have. As best we can.’
But it’s late now, I must go. Death-bed vigils are no longer part of my job. I don’t know whose job they are. I squeeze her hand again, and say goodbye. This time there is no response.

*

It’s proper dark by the time I leave, the path home is treacherous with mud and fallen leaves.
If I could stand above myself, and look down, I would see this: A cyclist rides a little too fast on an old railway line running beside some woods by a stretch of water. An ancient church yard, the squat church-tower lost in shadow. He disappears behind an embankment, then reappears. Now he is nothing but a point of light - his head lamp flickering behind the trees, now there, now gone. ■

Biographical note

Peter Dorward is a GP, medical educator, and author, based in Edinburgh, Scotland.

He is interested in medical philosophy: how the fabric of clinical medicine is held together by multiple fine strands of unexamined assumptions - assumptions of a philosophical kind, which we clinicians often find hard to see, and harder still to talk about. Peter believes that the capacity to think critically about the core nature of our work can help us better to know our purpose - it keeps us kinder and more attentive, and helps to protect us against alienation and burn out.

In his book, *The Human Kind* (Bloomsbury, 2018), Peter uses stories from his clinical practice to explore those philosophical concerns that are so enmeshed in our practice. He tries to tease out those values that sustain us, name what threatens them, and in so doing celebrate and cherish the profession that he loves.

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FLICKERS

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ARRIVING AT WORK

Sometimes, on my way to the office, I remain enveloped in the drama of the morning rush; it lingers heavily around me. Sometimes, in the solitary confines of the car, I express my frustration – at the lack of parking, at garbage in the street, at people driving selfishly. But sometimes, through that fog, it happens: I truly notice something. A leaf, a tree, the light. For that moment, my internal chatter and my slavery to time disappear. Awe shimmers through me.

Sometimes, the awe disappears when an anxious thought intrudes. Sometimes, the awe transitions into gratitude. Gratitude for these few moments of unclaimed time: in between home and work, I am neither mother, partner nor physician. I am just myself. I appreciate the silence. I decide that I do not need to obsess over time. I feel generous. These few moments, when savored, are a gem. They render the rest of my trip to work light and hopeful.

Usually though, by the time I walk through the office doors, I have stuffed my private self in my backpack and donned my professional self. Sometimes, it feels like a dead weight. Sometimes, like a privilege. Usually, I drop my keys on the desk. The clutter they make is my reality check, my wake-up call for the beginning day.

EARLY-DAY

Sometimes, I have a sluggish start to my day. Sometimes, my mind feels so sharp it is as though I am 20 again. Sometimes, I lean back as I listen to a patient. Sometimes, my hands hover tensely over the keyboard, fingers at the ready. Sometimes, my shoulders slump under the weight of the complexity. Sometimes I close my eyes at the sadness of the story. Sometimes, as a patient speaks, I think “This is a beautiful person.” Awe flickers in and out.

Sometimes, patients cross their legs as they sit on the exam table; sometimes their eyes are round with worry. Sometimes, their forearm tattoos are mysterious portals to their life; sometimes, it is their jewelry. Sometimes a patient complains about another physician. When this happens, I usually look at my hands with discomfort and even, shame. Are we all doing our best? Am I doing my best?

MIDDAY

Sometimes, I am running late. Sometimes, I am dissatisfied with the care I have given. Sometimes, I am upset at the demands people have because it is uncomfortable for me to push back. Usually, in any of these situations, my portals to awe shut down. My voice hardens and my body language stiffens, perpetuating negativity. Usually, on days like that, I do not allow myself to stop, and everything is a drag.

Sometimes though, a peaceful thought intrudes, and I remember that I do not need to be perfect. Sometimes, I recognize that it is not only about what I do, but also about how I am. Sometimes, it is a patient’s glowing graciousness that brings everything to a standstill. It fills the office and thaws my mood. Gratitude and peace flicker in and out.

Sometimes, I commiserate with a colleague. Sometimes, the exchange is like a thud: dull, and without an echo in either of our hearts. Sometimes our exchange is spot on and we laugh together. The joy and warmth of community linger like crackling embers.

END-DAY

Usually, my work is unfinished when I leave to pick up the kids. Usually, the trip to school is chaotic and rushed. Usually, I don’t have much time to think as the evening shift of dinner and homework begins. Sometimes though, there are moments of unexpected respite when everyone is busy and no one is calling me.

Sometimes, I use that time to look at my phone. Sometimes, I do an extra load of laundry. Sometimes, I lean against the kitchen counter and stop to reflect. I wonder if it is possible for me to be at peace with my work. I wonder if peace, like happiness, is not a goal to reach in the future, but something to be found in *this* moment. I wonder if I can create peace in my day, rather than waiting for peace to happen to me. Usually, my reflection is interrupted, and the respite is gone, leaving only a trace - like the cream and crumbs of a finished cake on an empty plate.

Tomorrow, the cycle will begin again. Tomorrow, the flickers will glow again. Tomorrow, I might ask myself at the start of my day: *how* do I want to be today? ■

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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MANAGING ESTRANGED RELATIONSHIPS AT THE END OF LIFE

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KEYWORDS: Hospice, Dying, Relationships, Moral distress

CASE DESCRIPTION

"There is so much love in this room," hospice nurse Martha said almost immediately following our introductions as two of the hospice team members that would be caring for Cheryl and her family. "I'm Cory, Dr. Cory Ingram, it is a pleasure to meet all of you," I had offered. I asked, "Cheryl, who is visiting you today?" "This is my husband, Randy, and in laws, Randy's parents, Doris and Larry and my brother and sister-in-law Mike and Judy. "This is my wife, Michelle, and Judy's husband, Bob," Mike explained. They were all very upbeat and it would have been hard to imagine for an outsider that Cheryl, age 48, was likely in the last two weeks of life having just decided to discontinue hemodialysis due to the progressive nature of her lung cancer, despite treatments.

"They are all visiting from Mantorville where Randy and I grew up, just down the street from each other", Cheryl added. Nurse Martha, interested to learn more about Cheryl and all that was important to her, inquired about her side of the family. "My parents live in the same house I grew up in, just down the street from Doris and Larry, and have for the last 53 years." Cheryl added. "We look forward to meeting them when they visit," nurse Martha offered. "Oh, they won't be visiting, we haven't spoken in the last eight years; not even since I've been ill," Cheryl said matter-of-factly.

In the process of getting to know Cheryl and her family we had come to learn that Cheryl had an estranged relationship with her parents. In all honesty, our hospice team's gut reaction is to look for avenues to repair that estranged relationship. Over the next 48 hours we probed, "How about if we reach out to them? We could give them a call and facilitate a conversation? We could include your minister if that would be helpful." Cheryl was gradually slipping naturally into the familiar and common state of dying hallmarked by sleeping more, eating less, and communicating less as well. We asked ourselves how best our team could help Cheryl and her family.

As members of an inpatient hospice team, we have come to identify a common theme, albeit infrequent, that raises specific challenges in providing end of life care – estranged relationships of birth family members, without any patient desire for rapprochement.

DISCUSSION

As hospice providers we consider the patient and the family as the unit of care. We provide bereavement support to the bereft. Our experience in providing end of life care to patients who identify an estrangement of a sibling or a parent who won't allow contact or attempt rapprochement can be difficult for our team. For some team members, these situations may lend to the experience of moral distress. It almost feels like we are failing the patient and the family by not finding an opportunity for reunion. We feel like we are failing because we are unable to facilitate the patient dying well with nothing left unsaid or undone.[1] We are failing because we are unable to create an opportunity for the things that matter most to be said before they are forced to say goodbye forever.[2]

In reflecting on the care we provide, and the experience of patients and families, we have developed a framework that may be useful to other clinical teams attempting to foster rapprochement when all efforts are being thwarted by the parties involved.

We devised a four-category approach to aid hospice teams in how they may choose to approach patients and families in estranged relationships. The first category is *Ceased Relationships*. These are the relationships that have ended prior to the dying phase and approaching end of life. The second category is *Ceasing Relationships*. These are relationships the patient identifies as relationships that simply need to be ceased but for many reasons have yet to be formally ended. We often find the patient not having the energy and/or desire to address these *Ceased* or *Ceasing Relationships*. We propose that clinical teams should follow the patient's lead in these situations. So, our recommendation is to affirm, accept, and normalize ceased and ceasing relationships as a normal part of life. Further attempts may actually strain your relationship with the patient or even worsen their end-of-life experience. *Ceased and ceasing relationships* are already over and past the point of repair.

Often the patients will want to focus their energy on relationships in our third and fourth categories in our framework. These are two categories that most likely capture the interest and energy of your patient and are also most likely to allow your hospice team to provide the support that you will be most successful in providing. These last two categories are the *Healing Relationship* and the *Celebrating Relationship*. *Healing Relationship* describes relationships that are in need and desire of rapprochement. *Celebrating Relationship* highlights those relationships that are whole and without anything left unsaid or undone in advance of the end of life. These relationships need celebrating and likely are being celebrated without much effort on the part of our teams.

When we meet with patients near the end of life it is possible that we will find them with relationships in all categories of our framework. They will have some relationships that have ended, some that need to end, some that need mending and some that are just fine the way they are. So how do we tailor our approach to each and every patient with humble regard for their whole person well-being? We suggest that in our partial roles as historians, counselors, clergy, and guides we start with active listening. Simply listening to their story and accompanying them as they share, and we solicit their story with tentative questioning to better understand their story and their experience. Stories will have characters and their life story will start to reveal the relationships in their life that are important. The relationship between them and their family members and friends. It may become apparent which relationships are ceased, ceasing, healing, or in need of celebration.

For relationships that are ceased and ceasing, perhaps our best approach is simply to listen and accompany. Perhaps bearing witness is the best therapy. For relationships in need of healing our role as counselor can also be augmented by our role as guides. In this unique role, addressing the healing relationship, we have the opportunity to guide the patient by offering the four things that matter most as a method of rapprochement that they may be able to use or request that you use in helping them heal that relationship that is meaningful to them.[2] The four things that matter most are: please forgive me, I forgive you, thank you, and I love you. Along these same lines, elements of existential distress may certainly arise and in your partial role as clergy, you can provide active listening, presence, and accompaniment to the scope of your particular discipline. For relationships in need of celebration, our role is largely to facilitate the environment for that to happen and find out how best to dose our involvement recognizing we may not be needed at all, and that is ok.

Balfour Mount wrote years ago of our roles in creating a space for healing and we believe that is the work of our team.[3] We hope that by identifying and categorizing the relationships as ceased, ceasing, healing and celebrating that hospice teams can better tailor their interventions to support the patient and their relationships near the end of life.

OUR APPROACH

What we failed to recognize is that Cheryl was at peace with the relationships of her life. Instead of feeling moral distress we had an opportunity to recognize that there was nothing left unsaid or undone in the setting of a ceased relationship. After 48 hours of fruitless probing, I finally inquired, “Cheryl, thank you for giving us a glimpse into what is most important to you right now. If it is ok with you I just want to clarify what I am hearing in regard to your relationship with your parents, is that ok?” “Sure.” “What I am hearing is that the relationship with your parents ended some time ago and currently your energy is focused on other relationships you would like to celebrate. Did I get that right?” I asked. “That’s right,” Cheryl confirmed. “Thank you for the clarification, Cheryl. We appreciate knowing how best we can help you and we’ll focus on celebrating the relationships that are most important to you. You keep us posted if there is anything else our team can help you with during these precious times.”■

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Biographical note

Cory Ingram, M.D., M.S., FAAHPM, is a Hospice and Palliative Care Consultant at Mayo Clinic. Dr. Ingram is the Director of Quality for Mayo Clinic Hospice and the Quality and Safety Curriculum of the Hospice and Palliative Medicine Fellowship. Dr. Ingram also shares his expertise through teaching as an assistant professor of both Palliative Medicine and Family Medicine with the Mayo Clinic College of Medicine and Science and a Co-Director of Communication in Healthcare in the Program for Professionalism and Values. Dr. Ingram is a fellow of the American Academy of Hospice and Palliative Medicine and has served in multiple capacities in the humanities and is the Editor in Chief of the AAHPM Quarterly and in his tenure, they are launching an Artist in Residency section to the publication. He has been featured at the Canadian Virtual Hospice and holds Storytelling workshops with Canadian health care institutions. Dr. Ingram is currently working with the palliative care units in Ottawa using the 55-Word story as a modality to improve meaning, purpose and quality of life. Dr. Ingram is also completing his Narrative Medicine Certificate from the University of Toronto Narrative-Based Medicine Lab and is working on a long form documentary photographic and narrative medicine project on caregiving through the end of life to complement his transitional caregiving research. Dr. Ingram is also co-author and collaborator on a forthcoming book focused on ethical care of the frail elderly in Europe and North American and a published photographer and poet.

Martha Siska, R.N., is a Hospice Care Coordinator for Mayo Clinic Hospice in Rochester, MN. She received her BSN from the College of St Teresa in Winona MN. She has enjoyed a wide variety of positions in her 45-year career at Mayo Clinic. She provided direct patient care for 30 years both in the Coronary Intensive Care Unit and later in the Neurosurgical Intensive Care Unit. She enjoyed the role of Nurse Manager of the Coronary Intensive Care Unit for over nine years. She went on to hold positions as Educator in Infection Prevention and Control, RN Extender for the Cardiovascular Services, and Case Manager for Mayo Clinic Health Services before joining the Mayo Clinic Hospice team in 2017 as a Hospice RN Care Coordinator. Martha has provided numerous formal presentations on hospice level of care to groups of patients and their families, medical residents and hospital-based nursing care teams. She has received the Service Excellence Award and the Karis Award. She has coauthored articles during her time in Infection Prevention and Control. Publications relevant to her experience in hospice care include: *Music Therapy Intervention to Reduce Caregiver Distress at End of Life: A Feasibility Study*.

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A MEDICAL STUDENT QUALITATIVE STUDY OF RURAL HEALTH CONCERNS, COMMUNITY DETERMINANTS AND WHOLE PERSON CARE

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KEYWORDS: Rural health, Medical students, Community determinants, Whole person care, Patient concerns

ABSTRACT

Background: Following a short rural health placement in the second year of medical school five students opted, as an extra-curricular activity, to conduct an exploratory research project into the wellbeing and health concerns of rural residents in the Wheatbelt of Western Australia. The project was conducted in collaboration with the local shires. The aim was to document, analyse and understand the health concerns and experiences of rural residents.

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Methods: A phenomenological research approach was employed. Seventeen rural residents selected by the shires, and four key informants, responded to open-ended interviews. Their narratives were subjected to a thematic analysis.

Results: The narratives described a wide range of health concerns relating to health services, mental illness, transportation, accommodation, marginalisation of the community, bureaucratisation of administration, community fragmentation and the desire for community partnerships. Frustration and inconvenience from community factors were associated with anxiety, depression, isolation, and loss of wellbeing.

Discussion: The respondents described dysfunctional infrastructure and under resourcing in a local rural community. They defined numerous health concerns related to deficiencies in community cohesion and integration. They illustrated how whole person health is impacted by the infrastructure and services available within a rural community. The narratives highlight the need for adaptation at the community level, following the example of Health in All Policies. Participants also highlighted the need for clinicians trained in supporting the functioning of the whole person within a fragmented rural environment.

BACKGROUND

"…illness is always experienced within the context of a particular life and in light of personal hopes and aspirations".[1]

The new Curtin Medical School (CMS) conducts a rural placement in the Western Australian Wheatbelt for second year students (Medical Student Wheatbelt Immersion Program) to demonstrate how family and the social environment influences health and social wellbeing in rural communities. Addressing the needs of rural health is a specific mission of the CMS. The local Wheatbelt shires and community residents strongly support this mission.

Prior to the rural placement the epidemiological picture of higher mortality and morbidity in rural Australia[2] is presented to the students as well as the inequalities in resourcing rural health services[3]. During the placement, the students are introduced to the local rural community context such as schools, industry, farms, community facilities, health services and family life. They interact with many local individuals and integrate themselves into the community. This experience exposes them to challenging local human issues in rural health at both the community and individual level and stimulated student interest in the wellbeing of the whole person[4]. This is the point at which this project was first conceptualised.

Collaboration between medical schools and rural communities is supported by the state government in order to promote rural health. As an extension of the student placement, some shire members expressed the view that documentation of local health needs by students could be of benefit to the community. This coincided with the interest of one of the authors (AH) to offer a more in-depth examination of rural health needs through a research project. Five students who had been enthused by their rural placement opted for this extra-curricular exploratory project to learn more of the individual health concerns and personal health experiences of local Wheatbelt residents.

Given the general health inequity and disadvantage of rural communities, including the Western Australian Wheatbelt[5], there was a good reason to initiate research into the local wheatbelt experience of rural health and wellness. For the students involved, this offered an opportunity to document and analyse individual narratives in order to understand the meaning of whole person care from the patient's perspective. For the purpose of this study, we defined 'whole person care' as providing the support and assistance necessary for individual wellbeing, independence, maintenance of function, achievement of personal goals and minimization of suffering. This concept embraces all supports and services an individual requires to maintain their quality of life. Given variation in the individual interpretation of 'health', the understanding of the experience of health, by necessity, needs to be described by the local participants themselves. Therefore, a strictly open-ended approach was adopted to learn about the community's subjective experience.

The aim was to document and understand the health concerns, experiences, and perspectives on wellbeing of Wheatbelt residents. The study was conducted by the students over the course of two years, concurrent with their medical school curriculum.

METHODS

Rural residents within the shires of Westonia and Merredin (population approximately 3,500) in the eastern Wheatbelt of Western Australia were interviewed. The study was developed and implemented in collaboration with these two shires and funded by the Wheatbelt East Regional Organisation of Councils (WEROC). Collaboration between Wheatbelt shires, Curtin and Notre Dame universities was already well established. The prospect of a joint research project was seen by the shires as a natural development. Planning and managing the project involved the active participation of the officers of the two shires and WEROC.

The participants were a convenience sample of 17 residents and four key informants invited by the shires. The selection was conducted by local shire officers. This was completed via a process of identifying local residents who were willing to be interviewed by the students. Both elderly and young residents were sought. No other criteria were applied. Most participants had already had some involvement with the university rural placement program which preceded the study. Fifteen of the participants were middle aged or elderly and two were in their early twenties. Three were male. Most were retired and were longstanding residents. A number were community volunteers and had served in key roles in the community over many years.

The focus on rural wellbeing is part of the Curtin University medical curriculum while the qualitative methodology to describe health concerns reflects the first author's (AH) career as a social scientist in public health and as a clinician in occupational medicine with a particular interest in disability and the patient's experience of illness. The other authors entered the project as medical students in the second year of the undergraduate medical program. They were self-selected on the basis of their interest in rural health and motivation to learn more about the subjective experience of health in marginalised communities.

A phenomenological research approach [6,7] was employed to disclose and elucidate the personal health experience of wheatbelt residents through subjective first-person narratives; the focus being the participants' own perspective obtained free from external directives. The aim was to determine the meaning of their health experiences to the individual. Interviews were open-ended and semi-structured using a general interview guide to prompt dialogue toward the resident's life experience, activities, social circumstances, opportunities, interests, and health concerns and services. The data were qualitative and experiential. Every effort was made to facilitate free and uninfluenced expression of the residents' opinions and experiences "allowing the phenomena to speak for themselves" [6].

The students underwent interview training prior to the data gathering. This followed discussion of the concept of wellbeing and of the importance of eliciting the respondents' perspective in order to understand the patient's subjective experience of illness. Interviews took place in participants' homes and in a shire office. The students interviewed in pairs, recording the content of the interview by hand. Interviews were 60 to 90 minutes in duration.

Ethics approval was granted by the Curtin University Ethics Committee following peer approval of the project by the Curtin Medical School. A participant information sheet and consent form were employed. Participation was voluntary and withdrawal at any time was acceptable.

ANALYSIS

The deidentified data were subjected to a content and thematic analysis to identify meaningful units or constituents [6] of the rural life experience. This was done in steps. Initially each researcher compiled a summary of the concerns and experiences documented in their handwritten interview notes. They also made note of any quotes they found particularly informative or poignant. The notes reflected each individual's experience and perspective and therefore varied in content and detail. These summaries were reviewed by the team and grouped according to their content area such as health care, housing, transport, etc. Based upon this initial thematic grouping the first author (AH) completed the final compilation of themes as presented in the results below. A report of results was circulated to all participants with acknowledgement of their participation. Feedback was received from the long-standing medical practitioner of the region who endorsed the findings as a valid description of the rural environment. No feedback was received from the other participants.

RESULTS

The health concerns described by the respondents have been grouped, with some overlap, into eight general themes. The quotations which follow are provided by the participants and are included here to illustrate their concerns and experiences. The themes were referenced by a number of different participants (Figure 1), with many participants discussing more than one theme (Figure 2).

1. Concern over medical care

“Many of the town’s difficulties relate to barriers to accessing care and to social inequalities.”

Concern was expressed over multiple aspects of medical care delivery.

The centralisation of specialist and procedural services has resulted in increased reliance on the larger towns and the state capital. The need for increased travel, including over-night stays have become commonplace in order to access services which previously were locally available. Locally “there are insufficient staff” for doctor services, aged care, mental health, and allied health services. These deficiencies significantly affect residents with fewer personal resources and greater medical need.

Professional and lay opinion was expressed that the medical system is dysfunctional through lack of leadership, teamwork, supervision, and coordination. “There is a lack of support for primary care by tertiary services. Children taken to Perth for psychiatric emergencies return with no long-term care plan. Some doctors lack networks to facilitate linkage and access to other services. Pharmacy services are not adapted to geographic isolation. The town’s health system may benefit from increased autonomy in deciding what services to provide.”

There is an opinion that investment has been misdirected into capital development at the expense of human services and staffing. This is illustrated by extensive hospital expansion and restoration accompanied by the closure of some local services.

Communication within the doctor-patient relationship was a focus of concern. For example, doctors for whom English is not the first language are seen as a barrier to the seeking of care. An Australian doctor who understands Australian country life is seen as a strength to the system.

The structure and function of rural health services is seen as problematic. It is felt that the rural areas are underserviced and that the provision of services is not adapted to the need. A major concern is “the mismatch of acute medical services and the health needs of the aging population”.

2. Concern over stress and mental illness

“Mental health has become a massive gap. The country is left to its own resources and self-medication is a big problem.”

It was commented by a retired social services professional that "there are no appropriate services for acute mental health episodes other than transporting patients to the local police station." The absence of preventive mental health education is felt to be an underlying problem, compounded by a "deficiency in availability and access to services."

"Methamphetamine and alcohol are significant problems."

"The stress of farming is a major health problem which is growing, yet support is not here. Farmers will work 20 hours a day and without sleep they are at risk of cutting corners." In addition, "there is the stoicism of country people and a reluctance to ask for help. Most youth with mental health concerns do not seek help." The nature of farming imposes social isolation and stress, complicated by the hardship of climate change. For the farming community, depression and suicide are a major concern.

Many respondents expressed their support for the Blue Tree Project, in which dead trees are painted blue in a community initiative to raise awareness for depression and the risk of suicide.

3. Concern over transportation and mobility

"Social isolation"

Transportation and mobility were cited frequently as a significant concern for both young and old; affecting local movement within towns, between towns and travelling to Perth. Concern was expressed by the elderly over their increased need to access services and their reduced personal mobility.

Demographic change is resulting in a smaller young population available to assist parents and grandparents with transportation and fewer volunteers to help neighbours. The aging population is placing greater transport demands on public transportation and on neighbours and volunteers. Reference was made by some to a reluctance to ask neighbours for assistance.

Train services have been reduced, timetables changed to less convenient times, and some night-time bus services have been stopped. Some train stations have not provided ramp access. The closure of some local bus services has been an unwelcome change placing greater reliance on the shire for community busing. The distance to drive to regional centres can be dangerous, due to animals on the road at night. The placement of elderly family members in aged care facilities distant from their own hometown is increasing the travel demands on relatives. This is a source of separation and isolation.

These concerns over transportation are not infrequently associated with feelings of stress and anxiety. In the case of younger residents who live on farms, the hazards of night driving are a deterrent to seeking entertainment in town. This detracts from the community hub and reduces opportunities for young people to socialise and interact with their peers. For the elderly, the reduced capacity to drive and the prospect of losing one's driver's licence are common causes of concern.

Difficulties with transportation underlie multiple concerns such as loss of independence, social isolation, general inconvenience, and risks. However, resources such as access to a golf buggy, the provision of safe, smooth footpaths and a community bus service provided by the shire are greatly valued by the elderly.

4. Concern over housing and accommodation

“Poor accommodation is fragmenting the community. People are waiting for houses.”

Concerns over accommodation and housing relate to the availability and location of appropriate housing for the elderly. Residential facilities may only be available in a distant town causing stress, isolation from friends and family and reduced independence.

5. Concern over an anti-rural bias

“There are negative views of the bush by people who don’t know what goes on in the bush.”

There is concern that the government does not identify with the circumstances and experience of the rural community. Furthermore, it was felt that government bodies lacked interest in understanding community circumstances and needs. “By contrast the community itself solves problems.”

6. Concern over decision making

“Bureaucratisation is a significant barrier at multiple levels in health care including access, availability, continuity, coordination, patient satisfaction, quality and cost.”

At the level of the whole community there is concern that decision-making and policy formulation is done centrally, without involvement, consultation or consideration of the local community and local providers. Numerous healthcare issues are attributed to centralised planning without local involvement. There is disappointment and frustration over community feedback going unheeded. Inflexibility is obstructing responsiveness to local needs and circumstances.

7. Concern over fragmentation of the community

“A big tragedy”

Many concerns relate to a breakdown in the social fabric of the community due to a perceived steady decline in community integrity, cohesion, and sustainability. Despite this, nearly everyone interviewed expressed strong affection for the country and rural living. Residents planning to move to the city were doing so only through force of circumstances and with regret.

Rural urban migration is affecting young and old. Limited educational and employment opportunities are cited as important reasons for young people leaving or planning to leave the country. Interesting career opportunities are not associated with living in a country town. Life in the country is not perceived as providing young people with a long-term future. Reference was made to generations being separated through parents remaining in the country while the younger generation pursue their lives in larger centres. Consequently, aging parents in the country lack local family help and rely on community support from volunteers, neighbours and services. Family members need to commute long distances to see one another which brings with it unavoidable difficulties. Concern was expressed over the increasing difficulty to find volunteers to provide essential services. This was attributed to the ageing demographic and fewer younger people in the community.

The family farm has been the mainstay of the Wheatbelt but now “30% of the farms are corporate, run by managers and FIFO (fly-in-fly-out) workers whose lives and families are elsewhere”. This industrial change is seen as undermining the traditional social structure of the country and is described as “a big tragedy”. This is detracting from the social capital of the region and reducing community self-sufficiency while increasing reliance on services. The loss of the position of community officer is perceived as a backwards step and one that fails to respond to the need for community development.

There is concern over alienation within the rural community, presenting in various ways. Reference was made to the presence of racism, ageism, and rejection of newcomers by some sections of the community.

8. The desire for partnership

“We know the problems.”

There is concern over the complexity and multiplicity of issues facing the Wheatbelt. While the problems are well known to the community, the solutions are not. There is a desire for partnerships to find ways to manage issues and to promote advocacy and change. Collaboration with universities was cited as a desirable partnership. This could help document the need for change and promote awareness of rural health and wellbeing issues.

DISCUSSION

Community-level factors were identified overwhelmingly as the major source of health concerns to individuals at the local level. Infrastructure such as health care, transport, housing, and their governance were described as unresponsive to rural health and wellbeing needs. The problems identified included a broad range of complex, interweaved community determinants of health related to demographic changes, socio-economic factors, rural geography, resource provision, industrial changes, educational and career opportunities. These population-level findings are consistent with major sources of Australian rural health data[2,3,8,9] and illustrate the importance of the strategy of Health in All Policies[10] to health and wellbeing at the local level. At the same time, this defines the role of the whole community environment as a health determinant. It also demonstrates the scope of the demand on the clinician to practice with sufficient wholeness to facilitate the patient’s optimal functioning in an unsupportive social context.

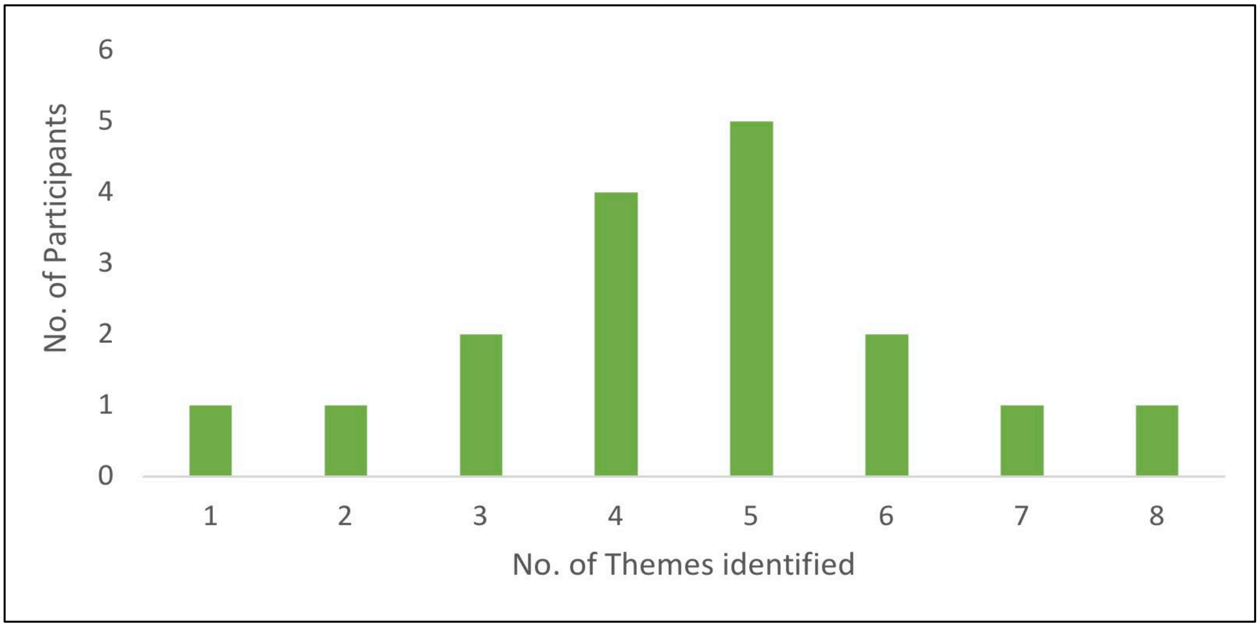

Fig 1. Number of themes identified by each participant

This association of community dysfunction and health is consistent with the extensive scientific evidence relating suicide[11], mental illness[12] and general morbidity, mortality, and life expectancy[13] to loss of community cohesion.

The participants have illustrated how ecological principles of community cohesion[14] are not being met:

1. Service sectors are functioning as silos without application of the principle of holism or consideration of interdependence and relationships within a wider system.
2. The steady decline in local social capital and resources such as services, and career and educational opportunities signal unsustainability within the community.
3. Loss of demographic diversity is weakening community capacity to cope with functional demands on self-reliance and volunteerism.
4. Community equilibrium and balance is being lost through outward migration, the aging demographic and loss of family farm ownership.
5. The network of interdependence within the community is being weakened while dependence on external resources is being imposed upon the community.

The result is a social tension in rural communities. While participants recognise the problems in the community; they feel disempowered to change the situation. They feel marginalised and excluded from consultation, planning and decision making. Community governance is perceived as being top-down without local participation.

In addition to the frustration and inconvenience associated with service infrastructure the participants acknowledge the presence of generic problems such as intrinsic health risks of farming, geographic isolation of rural life, climate, and the stoic personality of rural people.

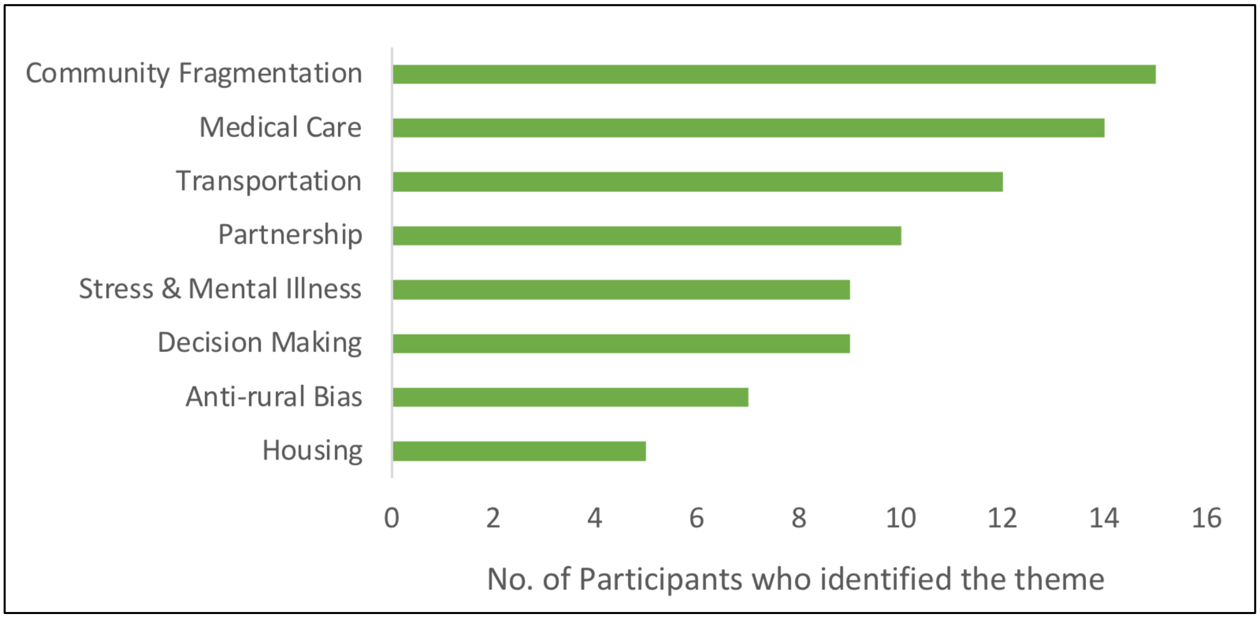

Fig 2. Frequency of theme identification by participants

These findings stress the importance the local community environment plays in whole person care and health. Familiarity with the patient's social environment and acknowledgement of its importance to the patient is therefore an important baseline for the clinician. A critical step in whole person care is understanding the local environment from the patient's perspective and knowing the patient's experience of how personal functioning in everyday life is impacted by their environment. As Eric Cassell[15] points out the clinician needs to address the patient's own goals and purposes. Our findings highlight the need of the clinician to consider the obstacles to these goals and purposes posed by the patient's own community circumstances and experience. Then knowing the patient's personal situation; the clinician can utilise both medical and social prescribing[16] to guide the patient in adapting to their situation to achieve optimal wellbeing and functioning. Of clinical relevance and of specific concern in everyday living to the participants in this study were such things as access to help, maintaining independence, isolation and contact with others, coping with stress, depression and anxiety, securing safety and the need to travel due to physical isolation. The medical and social demand on healthcare in this rural setting requires both public health and whole person care to be applied with an understanding of the community context. Healthcare with a strong orientation towards the social environment has much to offer. Hopefully local support from medical schools and governments will continue to grow.

In reflecting on the methodology used in this project the qualitative phenomenological approach has facilitated the free expression of the residents' views. From the perspective of the student researchers, the experience of designing, interviewing, and analysing these narrative data has provided an in-depth exposure to individual and community issues in rural health and their joint relevance to whole person care. The participants' stories have provided both a holistic systems view of the community and a personal perspective on individual rural lived experience.

The partnership of university and wheatbelt shires has provided a valuable collaborative framework for education, research, and the enhancement of understanding of the local health experience of the rural community. The active involvement of students in the documentation and analysis of the participants' health concerns has increased awareness of the subjective experience of health at the local level which is essential to whole person care. This is a win-win partnership.

The sobering message from this project is the inequity and marginalisation of rural communities. This is despite the overwhelming evidence that loss of community connectedness and integrity is a major determinant of ill health, loss of wellbeing and general social dysfunction. This disempowerment is associated with a perceived anti-rural bias and exclusion of the community from its own policies and decision making. The belief of rural residents that the community should be included as a respected equal in planning and policy making has been echoed widely. Writing in support of consumer involvement in global health, Nigel Crisp characterised the change which is needed as "turning the world upside down"[17]. The residents defined community development as a major unmet need for rural health. Indigenous Australian authors writing on community development propose an approach based on "listening, respecting, acknowledging, trusting, relating and understanding."[18] This captures the sentiment that would respond favourably to current rural health concerns.

It is hoped that this project adds positively to the voice of the community and participating shires in their desire for evidence to support advocacy for local development and services. The project has given the students a role in contributing to the local community which generously hosts the rural placement of medical students. For the students the in-depth exposure to the personal experiences of local residences provides the opportunity to identify previously unidentified career opportunities in rural health and whole person care where health providers are greatly needed.

A number of limitations need to be acknowledged. Resources were limited. As an extra-curricular activity student time and availability were constrained. No academic credit or formal time were allocated and therefore progress relied entirely on personal commitment and interest. There was no precedent for undergraduate student research in the new medical school and an administrative framework for this type of activity was not yet in place. Funding was limited to external community funds for travel and accommodation.

The scope of the project was shaped by the students' prior rural health placement in which the health of the elderly featured prominently. Aged care was also a high priority for the wheatbelt shires, and this was a research topic they readily endorsed and for which recruits could be easily found. For these reasons a convenience sample was selected by the shires. This sample was biased toward the elderly and those involved in the community. As a consequence, health concerns of other age groups and occupational groups were potentially underrepresented. While the data identified community-wide concerns there was no specific focus on children, youth, families, the working middle aged and Indigenous groups. Hand-written notetaking and failure to audio-record the interviews led to loss of some detail and precision in data gathering. This was compensated for, to a degree, by each pair of interviewers documenting the interview and by validation of the findings by a key informant.

Follow-up interviews would have increased understanding of the issues which would have benefitted both the community and the students' educational experience. It is reassuring to note the consistency of our findings with other larger studies of Australian rural health. Limiting the study to two towns was not the intention. Support and funding from WEROC to include the three other towns in the area had been approved but unfortunately this could not be pursued due to the COVID-19 pandemic. To date the opportunity to use this project to contribute to the CMS curriculum has not yet arisen. Strengths of the project were involvement of the students in all aspects of the research. The phenomenological approach demonstrated the relevance of the person's individual experience of health. Documentation and analysis of the patient's narrative and the focus on wellbeing illustrated to the students a method to help understand social disadvantage.■

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CONFLICT OF INTEREST

There are no competing interests.

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Biographical note

Andrew Harper works as an occupational physician. He is trained in public health and behavioural sciences. He has had an academic career in clinical epidemiology, medical education, and occupational health. His principal interests are the patient's experience of health and the role of the community environment in health and wellbeing.

The co-authors came to this study as second year medical students stimulated to understand the lived experience of rural health. Two had undergraduate degrees, one in nursing (Kahla Edwards) and the other in science (Tessa Corbett) and three had started medical school directly from high school. Now they have all graduated in medicine and are practicing as junior doctors.