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### The patient, the whole patient and nothing but the patient

#### Clinical competence and limiting factors

In this short opinion piece, carer and consumer advisor Belinda MacLeod-Smith challenges us to consider crucial elements of whole patient care, and how they can be impacted by limiting factors.

aring for someone with ongoing, occasionally acute, health needs means I have a high level of interest when it comes to hospital-based services and the concept of 'whole patient' care. My husband and I often reflect that as a survivor of heart failure, severe sepsis and total organ failure following heart transplant, it's technically a miracle he's still alive and thriving.

His survival is an absolute testament to the medical expertise available as part of Australia's system of universal healthcare. We're always careful to include the word 'medical', because there's a parallel, defining element of his experience in multiple wards, emergency departments and intensive care units in six hospitals across three states over nearly ten vears.

That defining element is that he's often felt like, in his words, a 'meat-bag'. While this could be expected during the times he's been sedated and ventilated, his role as a passive recipient of care has sometimes been enforced even when he's been conscious, lucid and absolutely capable of participating in decisions, or at least conversations, about his care.

More often than not, our experience has been that we should expect and accept medical competence, and not much more. Of course there are sparkling outlier moments, times of breathtaking humanity and consideration, but those moments are exceptions.

While I'm beyond grateful for the medical system that's saved his life multiple times, I believe we need to go forward with open eyes about the multiple system elements that have to change before we can achieve sustainable, agreed versions of whole patient care.



"A whole patient understanding is crucial. Quite simply, people don't perceive themselves as a collection of conditions. Health is personal, intertwined with people's individual perceptions and mindsets, with the environments in which they live and work and the people with whom they interact." (Dudgeon 2015)

I believe the most important thing to consider is whether we (healthcare workers, patients, families and carers) have a shared understanding of what's meant by whole patient care. An online search will throw up a multitude of terms (more than 2,400,000) in relation to 'whole patient care'. Holistic care, person-centred care, and patient-centred care are other terms I've heard. I see hospital vision and mission statements by the dozen that reference 'putting the patient first' or 'the patient at the centre'.

In my background reading, I found one particular article really helpful. In her 'Understanding the whole patient' article, Kate Dudgeon suggests a four-layered model for 'whole patient' care (Dudgeon 2015). Dudgeon's research with patients found the following four areas as key factors in a holistic model of care: medical, psychosocial, attitudes/beliefs and information/communication preferences.

Medical: Earlier, I used the phrase 'medical competence'. Of course medical condition or need is central to every patient. If my husband hadn't received competent clinical care for heart failure, nothing else would have mattered. What Dudgeon explains as important to note here is that if an individual has a number of health issues, they see their medical needs as whole and interconnected. My



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husband never saw himself split into the separate conditions of heart failure, kidney failure, or a toxic thyroid—he was all of these things together—it was the specialists and outpatient clinics that were separate.

**Psychosocial:** Along with our medical condition is our psychosocial state: our mental and emotional state, social systems, and functional capabilities. Does a person suffer from anxiety? Are they depressed? Do they have a functioning and positive social support network and environment? This layer is important to understand because it can either inhibit or enable a person's ability to actively take part in caring for themselves.

I've often found myself to be an informal advocate for patients and families I've met in waiting rooms, or who have contacted me through the transplant community. Like my family, they've had to travel from interstate or regional areas to receive medical care, and don't have their usual 'community' around them. This lack of a support network creates additional logistic and emotional stress that can have a massive impact on both care experience and care outcomes.

Attitudes and beliefs: Dudgeon's article suggests the next whole patient component addresses attitudes and beliefs, which she breaks into two parts. First are the beliefs or perceptions formed over time about your own health and care, often based on your own experiences or those of family and friends. The second part is the attitudinal category we fall into, which depends largely on how much involvement we have in our own health and care. My husband, prior to becoming acutely unwell, would have been categorised as a minimalist-someone who denies a health condition or does the bare minimum recommended by a healthcare provider. At the other end of the scale, I'm definitely a maximalist, someone who proactively seeks health information and is engaged in my own care planning. My husband is also a great example of how this category can change over time. This is probably best shown by his weekly ritual of prepping his thrice daily post-transplant medications, around 130 tablets every week, with 15 different scripts of varying strengths and quantities—he's got a lot of 'skin in the game' when it comes to medication adherence.

**Information and communication:** The last element of Dudgeon's model of whole patient care is information and communication preferences. Simply put, this relates to how someone learns, when they're



66 IF AN INDIVIDUAL HAS A NUMBER OF HEALTH ISSUES, THEY SEE THEIR MEDICAL NEEDS AS WHOLE AND INTERCONNECTED 99

open to learning, how they seek out information, and how they prefer to exchange information with a care team. Personally, I love a detailed brochure or pamphlet that I can take away, write notes on and absorb. My husband likes a short conversation, and would be happy in a world where everyone communicated using Twitter rules—280 characters or less.

#### **Limiting factors**

When I think about the whole patient model described by Dudgeon, I'm reminded of a concept used in agricultural science—Liebig's Law of the Minimum. Liebig's law states that crop growth happens at the rate permitted by the most limiting factor. So growth isn't dictated by the total resources available, but by the scarcest resource (limiting factor).

This concept was originally applied to plant or crop growth, where it was found that increasing plentiful nutrients didn't increase plant growth. The growth of a plant or crop can only be improved by increasing the amount of the limiting nutrient (the one most



scarce in relation to need). I believe this 'a chain is only as strong as its weakest link' concept is the perfect metaphor for whole patient care.

Yes, a patient can survive with the essential nutrient of medical care, but whole patient care, the kind of care where a patient thrives, can only happen if we're conscious of all the 'nutrients' needed for wellbeing.

#### **66**THE KIND OF CARE WHERE A PATIENT THRIVES CAN ONLY HAPPEN IF WE'RE CONSCIOUS OF ALL THE 'NUTRIENTS' NEEDED FOR WELLBEING 99

So what's it going to take to get us there? As I think about what kind of actions 'shake things up' and act as positive disruptors in the pursuit of whole patient care, I think we could use the agricultural metaphor to consider and discover the limiting factors within a hospital system.

In caring for my husband and another close family member, I've seen a smattering of well-intentioned approaches that theoretically enable better whole patient care. Most recently, I experienced bedside communication whiteboards. I was so excited when I first saw them, and thought how they could be a truly powerful platform to focus attention on all the elements of whole-patient care.

Here's the thing. During a recent admission, I saw that many bedside communication boards on the ward were blank, or had the wrong date and no pens to write with, or erasers to clean them.

As a whole patient care initiative, those boards were a complete mirage of hope. When I asked about pens, I was told there was budget to buy the boards and get them up, but not for pens. When I asked about unanswered questions and incorrect days/ dates (horrid for someone experiencing delirium) I was told that staff didn't have time, that they didn't have capacity to update boards or even have conversations about them.

So what are the limiting factors at play here? If we accept the notion that whole patient care involves paying simultaneous attention to all the things that contribute to a person's wellbeing, we need to consider paying the same kind of attention to hospital systems. In the case of the whiteboards, I can only guess more attention needs to be given to culture, governance and possibly funding - some pretty critical limiting factors.

Let's get excited about the patient, the whole patient and nothing but the patient. But please, before we start rolling out well-intentioned initiatives let's make sure there's a clear understanding of any limiting factors that could result in us sitting around, staring at empty whiteboards.

#### **KEY POINTS**



- The condition-specific focus of health services is at odds with the intrinsic. holistic nature of humans who do not see themselves as a collection of conditions
- We can consider four spheres of need: medical, psychosocial, attitudes/belief and information/communication
- Like healthy growth in plants, achieving optimum whole patient care is dictated by the scarcest resource or limiting factor



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