

Myths, Realities, and Pathways Forward: A Patient's Thoughts on Person-Centred Care

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Introduction

In an era of increasing complexity and fragmentation within the healthcare system, the concept of person-centred care (PCC) has emerged as a transformative approach to delivering high-quality, patient-focused services [1, 2]. We patients certainly applaud PCC's emphasis on treating us as whole persons, rather than just our illnesses or conditions, and most of us are intuitively excited about our voices being heard and patients being empowered as active partners in our own care.

The concept "Person-Centred Care" may sound straightforward and even little beyond "stating the obvious." In reality, many barriers frustrate its daily practice adoption, and there is a real danger of PCC remaining merely a politically correct tagline [3]. Misconceptions and misunderstandings about PCC may be at the forefront of hindrance [4]. We patients, as key stakeholders, are uniquely positioned to dispel the

myths, highlight its true value, and prevent it from being dismissed as "healthcare clichés" as a result of "slogan fatigue."

Myths about PCC

One prevailing myth is that PCC is all about "pleasing the patients." Whilst our "customer experience" is certainly important, PCC should encompass so much more: truly understanding our individual needs, preferences, and goals and tailoring the care delivery accordingly. In fact, the interactive process of engagement and partnership would be particularly valuable in certain difficult or unpleasant clinical settings, such as breaking a bad news or discussing a tough call.

Another common myth is that PCC places an undue burden on healthcare providers, adding to their already overwhelming workload. I would respectfully argue that, when implemented correctly, PCC can actually help mitigate provider burnout by fostering improved communications, stronger partnership, and a more coherent and sustainable work environment [5].

Personal Reflections on Value Propositions of PCC

At its core, PCC recognises that each patient is unique, with our own lived experiences, social determinants, and personal preferences [6]. By focusing on the whole person, rather than just our specific medical conditions, PCC enables a more comprehensive and tailored approach to care [7].

As a lawyer who has experienced the rigors of both a legal education and the healthcare system as a patient, I find intriguing parallels between these two domains. The journey of navigating the healthcare system with medical conditions, diagnoses, treatments and prognoses, strikingly mirrors the arduous path of legal training. Both arenas demand not only the transmission of knowledge but also the cultivation of skills, the presence of trust, respect and well-reasoned disagreement, and a shared commitment to the improvement and well-being of the less experienced party, who travels from a state of necessity to a state of freedom with better literacy and more autonomy and self-determination. Both domains call for cross-disciplinary insights and the exchange of best practices that are both holistic and individualised.

As a law student, I was encouraged to challenge legal precedents, present alternative interpretations of statutes, and engage in Socratic dialogues to deepen my understanding of legal doctrines. This pedagogical approach proved indispensable in sharpening my critical thinking abilities and honing my problem-solving skills, both of which were indispensable in my future legal career.

Similarly, born with a 50% chance of inheriting ADPKD, I was destined for close relationship with my “renal professors”. – I had hoped for a speed date, but it turned out to be a lifelong marriage, with a new life relaunched after my very fortunate and successful combined liver and kidney transplant in 2018, the day following my 50th birthday. Within the realm of renal care, an effective and supportive patient-provider relationship assumes great significance for navigating the knowns and the unknowns inherent in nephrology and medicine in general.

I remember opting for catheter access for my haemodialysis instead of an AVF. Being able to continue my routine legal practice – conducting conference calls, typing legal documents, counselling clients over the phone with my unencumbered hands was essential for me during the in-centre sessions. This choice not only helped me manage my renal failure but also provided mental relief, even if it was not the best option according to

medical guidelines. It was a matter of my personal value and preference, and a decision made collaboratively with my healthcare provider.

Discussing the possibility of a combined liver and kidney transplant as part of my treatment plan was another remarkable experience. I went through a range of emotions, from disbelief and concern to eventual acceptance and pre-surgery anxiety – a true mental rollercoaster. Provider communication, trust, and partnership accompanied me through the journey.

I also faced the dilemma regarding how much I wanted my family to appreciate my situation. Whilst I did not want them to be overly concerned, I felt the need to prepare them for the worst. The holistic counselling I received had equipped me with deeper understanding of my conditions, facilitating a more rational and proportionate presentation to my family members, taking into account their capacity for difficult news.

I am sure I would not be the only one who has encountered unique challenges in patient journey. Person-centred approach does make sense when the providers treat us as whole persons rather than merely a set of medical conditions. As a lawyer and a patient, I have developed a profound appreciation of, and become a strong advocate for, PCC.

Impact of PCC on Quality and Safety of Healthcare Delivery

The implementation of PCC can be a powerful lever for improving the safety, quality, and sustainability of healthcare delivery, ultimately leading to better outcomes for both patients and the healthcare system as a whole (Fig. 1) [8, 9]. From my perspective, PCC presents win-win opportunities in many settings and for multiple stakeholders.

PCC Emphasis on Deep Level of Engagement and Collaboration Mitigates Patient Safety Risks

When providers truly listen to patients, clarify our concerns, and involve us in decision-making, it helps identify safety risks [10]. We patients are often the first to notice discrepancies or unusual changes in our symptoms or conditions, and PCC empowers us to communicate timely to our providers to mitigate risk of delays or errors, such as late finding, misdiagnose, adverse medication incidents or inappropriate procedures.

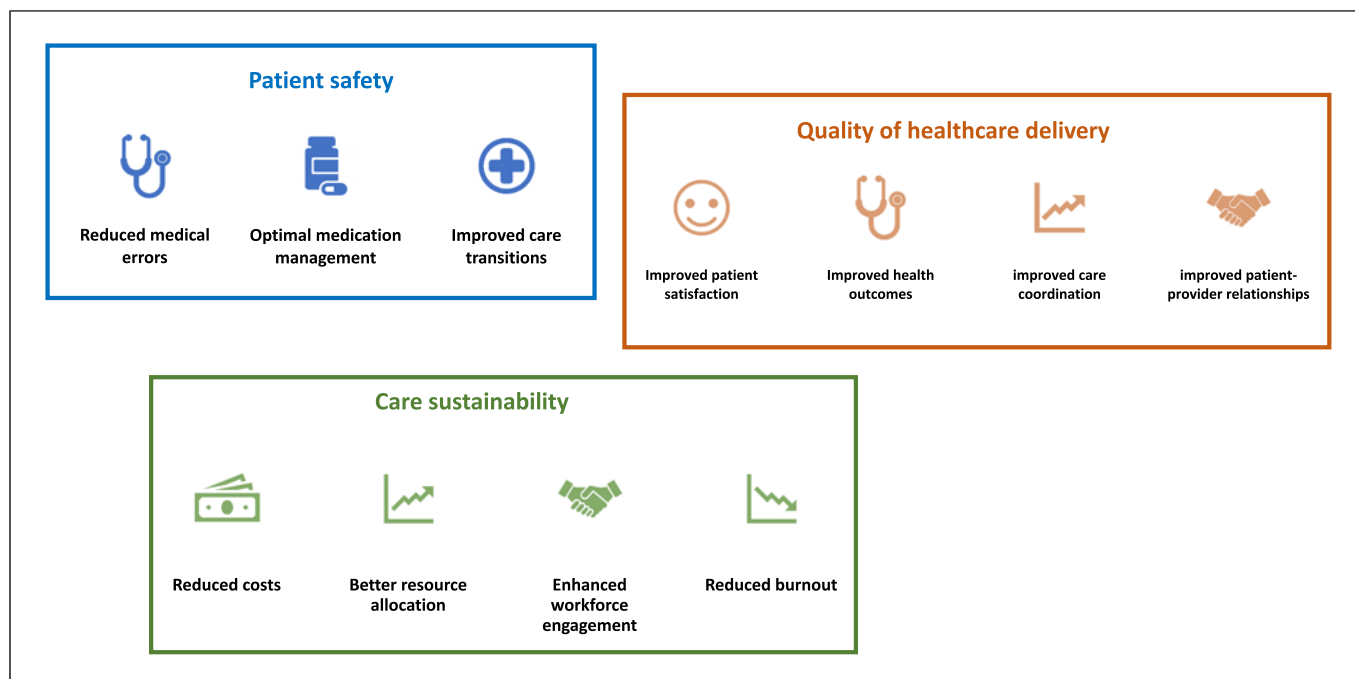


Fig. 1. Value propositions of PCC.

When providers work closely with patients to understand our medication history, our lifestyles and personal preferences and explain to us in plain language about the rationales, the pros and cons of particular medication, it can lead to our improved drug literacy, better adherence, fewer adverse drug events, and more optimal therapeutic outcomes.

As patients with multiple chronic or acute conditions, we would certainly like to see the coordinated, team-based approach in care transitions, reducing the risk of communication gaps, medication errors, and other safety issues to better facilitate smoother and safer care transitions.

PCC Has a Profound Impact on the Overall Quality of Healthcare Delivery

When patients feel being heard, respected, and actively involved in our own care, it leads to higher level of satisfaction and engagement. This, in turn, can improve treatment adherence, health outcomes, and the overall patient experience.

By aligning care plans with the patient's goals, values, preference, lifestyle, and lived experience, PCC helps ensure that the treatments and interventions provided are

best tailored at the individual level. This can lead to more accurate diagnoses, more appropriate treatment plans, and better overall care quality.

The collaborative, team-based approach of PCC facilitates the integration of various healthcare disciplines, ensuring that our needs are addressed holistically. This can lead to more streamlined, comprehensive, and personalised care delivery. The fostering of better communication, deeper understanding of the patient's unique circumstances and shared decision-making under the PCC model can certainly contribute to a stronger, trust-based partnership between patients and their providers [6].

PCC Can Have a Ripple Effect in Amplifying System-Level Sustainability and Benefits

Improved patient safety, better health outcomes, and enhanced care coordination can lead to reduced utilisation of more costly resources, such as emergency department visits, hospital readmissions, and prolonged hospital stays. By focusing on the patient's unique needs and preferences, PCC can help healthcare organisations allocate their resources and direct investments towards the interventions and services more reflective to true

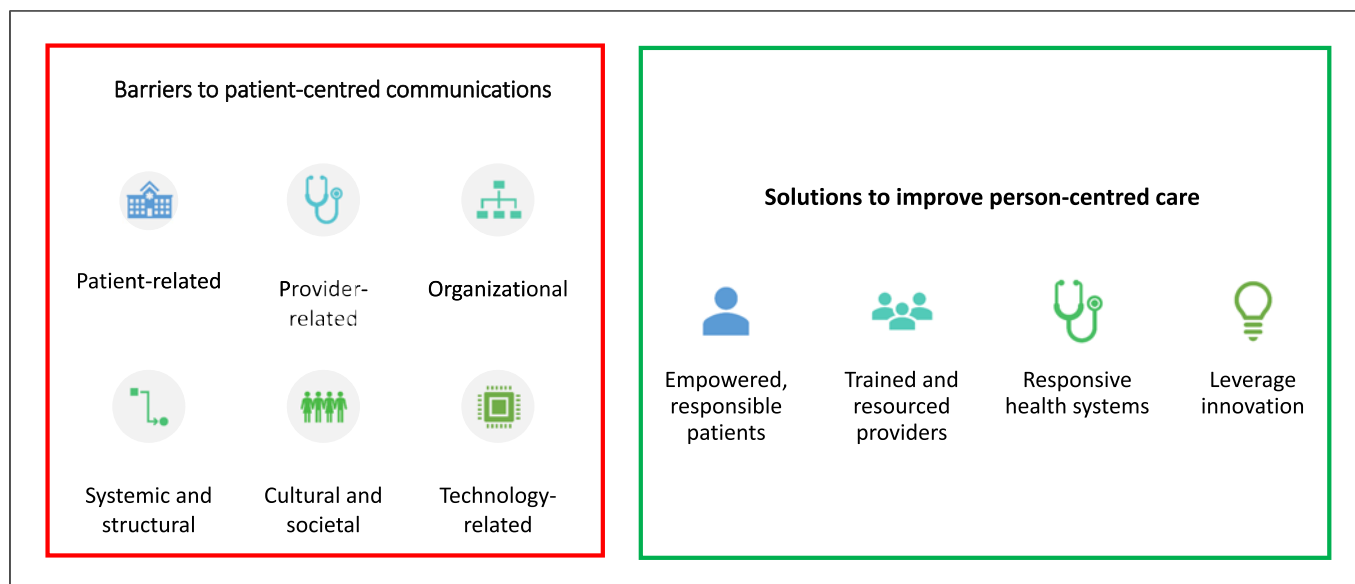


Fig. 2. Barriers and solutions to PCC.

realities. As elaborated below, PCC can also have a positive impact on provider well-being and job satisfaction, leading to improved workforce retention, team cohesion, and quality consistency.

Mitigating Provider Burnout through PCC

Whilst the benefits of PCC to patients are apparent, I would argue further that this approach can also have a positive impact on providers and overall healthcare system [5]. When providers are able to engage in meaningful, person-centred interactions, they shift away from a transactional, disease-focused and volume driven model of care towards a more holistic, relationship-based approach which emphasises effective communication, streamlined process, and team-based care delivery. This aims to alleviate the administrative pressures that contribute to provider burnout, allowing clinicians to focus more on what drew them to healthcare career in the first place – embracing humanity, fostering relationships and staying relevant to improving the lives and experiences of their patients.

The sense of purpose, reward, and achievement associated with PCC model and the collaborative features of PCC can have a positive impact on provider well-being in a more supportive work environment. Healthcare organisations that implement PCC can also reap the benefits of improved provider retention, en-

hanced team cohesion, and a more stable workforce. The synergies between PCC and provider well-being can create a positive feedback loop, leading to better experiences for patients, providers, and effectiveness of healthcare system as a whole.

Implementation Barriers

The push for PCC in healthcare has gained significant momentum in recent years, as both providers and patients recognise the immense benefits it can bring. However, the journey towards truly embracing PCC is fraught with a multitude of barriers that continue to hinder progress (Fig. 2). Understanding and addressing these challenges is crucial if we are to transform the healthcare landscape and put persons at the true centre of the care experience [1, 2, 11–15].

On the patient side, disparities in health literacy, cultural and language barriers, and a lack of confidence or empowerment can all contribute to the difficulty in achieving true PCC. In the era of information overflow, making judgment on information trustworthiness could be challenging for certain patients, otherwise sensible individuals who are not necessarily well versed in healthcare matters. Patients who have experienced negative interactions with the healthcare system in the past may also harbour a deep-rooted distrust, further hindering their buy-in.

We have observed healthcare providers often grappling with heavy workloads and time constraints, leaving little room for the kind of in-depth, person-centred communication that is essential to PCC. Additionally, a lack of training and skills in this area, coupled with conscious or unconscious paternalistic attitude, can make it challenging for providers to embrace the shared decision-making and patient empowerment.

We have been told that rigid, hierarchical structures that have long dominated the healthcare industry can pose significant obstacles to PCC. When efficiency and productivity are prioritised over the patient experience, it becomes difficult to foster the collaborative, personalised approach that PCC requires. Lack of investment in patient engagement initiatives and the persistence of siloed, fragmented care coordination further compound the problem.

At the broader, systemic level, certain models of fee reimbursement, budget allocation or performance assessment may result in, or even incentivise, volume over value which can pose significant obstacles to PCC. Regulatory and policy constraints may also hinder the implementation of innovative, person-centred approaches, while the inadequate support for social determinants of health can undermine the holistic, personalised care that PCC aspires to provide.

Underpinning many of these barriers is the deeply ingrained paternalistic culture that has long permeated the healthcare system. Societal expectations of patient passivity and deference to providers can further entrench these traditional power dynamics and hinder the shift towards a more collaborative, person-centred approach. The increasing role of technology in healthcare has also introduced new challenges to achieving PCC. Poorly designed or user-unfriendly IT systems, concerns about data integrity and security, and unequal access to digital tools can all hamper the integration of technology in a way that truly supports the PCC model.

Pathways Forward for Implementing PCC

We believe that addressing multifaceted barriers to true PCC will require concerted, multipronged efforts, involving paradigm shift by individuals, providers and patients, and institutional cultural and structural changes (Fig. 2). Fostering a culture of empathy, respect, and shared decision-making is crucial, as is investing in provider communication and patient engagement trainings and patient medical literacy improvements. We patients should and can be empowered and equipped

with the tools and resources to improve our health and medical literacy and advocacy skills, to actively participate in our own care by being our own advocates. After all, the ownership of our health rests with our own selves.

Providers need comprehensive development in necessary skills and mindsets to embrace PCC. Healthcare institutions must be willing to restructure their systems, align incentives, and invest in patient engagement initiatives. Medical schools have a critical role in embedding the PCC concept and practice in their academic, clinical, and ethics curriculums for the future generations of practitioners.

At the systemic level, policymakers and regulatory bodies must facilitate the necessary changes to enable a more person-centred, value-based healthcare ecosystem. The emergence of artificial intelligence tools has created new dynamics in healthcare delivery. On the positive side, empowered patients would be more effective users of the emerging AI tools as well as educated or passive contributors of data to facilitate machine learning processes to further sharpen these tools. As a patient, I am enthusiastic about AI tools taking to a new level the knowledge transfer process, patient empowerment, provider-patient partnership in collaborative problem solving.

Conclusion

Under the PCC model of both holism and individualization, we patients expect our providers to be our effective “polypill.” In the context of nephrology, a good multidisciplinary kidney care team should really be the renal version of competent primary care professionals – having a basic understanding of us as persons who happen to have kidney conditions, you may well conclude that we need not only renal treatment, but monitoring of other conditions or risk factors, or lifestyle changes or social or emotional support, or even, say, marriage counselling – referring to other specialties as appropriate, but never losing sight of the big picture of patients being treated as whole persons, not just a set of medical conditions.

PCC is never a one way street. No providers or healthcare systems can afford to underestimate the resourcefulness of patients under the PCC model: we can be effective eyes and ears sensing clinical signals for our providers; our lived experiences are valuable contextual factors of care plans for both symptoms and root causes; our active participation in studies can inform data points relevant to providers’ clinical and research efforts to benefit a wider population; our trust and empathy towards our providers can create a powerful advocacy

alliance for necessary systemic reform and better resource allocation. PCC is not just a lofty ideal or tagline – it is a pragmatic approach that can improve patient outcomes, increase provider professional satisfaction, and ultimately, create a more sustainable, equitable, responsive, and compassionate healthcare landscape – for all.

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of your providers and forming strong allies in advocating for paradigm shift towards person centred care model. It is my hope that the work here will echo your experiences and contribute to improving the lives of those affected by chronic kidney and other diseases.

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To the wider renal community – patients, families, and caregivers – thank you for your resilience, your inspiration, and your tireless advocacy. It is my honour to amplify your voices through this work, and I am committed to continuing the pursuit of person-centred care alongside with all of you.

Conflict of Interest Statement

I have no conflicts of interest to declare.

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