


Person-centred care and measurement: The more one sees, the better one knows where to look

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Determining the quality of a health system is a complex and challenging endeavour. The variety of perspectives needed to determine quality means that increasingly complex measurement frameworks are often employed. Providing the best possible health care has always been a priority for health system leaders, individual professions and individual professionals. But the importance and significance of measuring quality has increased since the evolution of quality-improvement methodologies for health-care quality standardisation in the 1990s.¹

Audit and feedback systems evolved into quality-control methods with the increased industrialisation of health systems. As the patient voice became increasingly important, with the rise in advocacy groups and patient-representative organisations, the focus on controlling the quality of services through a managerialist ideology was challenged. Broader, more inclusive, approaches to quality were embraced. Quality-improvement methodologies aim to adopt an inclusive approach to ongoing quality enhancement, ensuring that services are continuously developed and improved.² This evolutionary context is important when considering the measurement methods that dominate health systems. To some extent, it could be argued that while health care cultures have shifted their focus from one of control to improvement, approaches to measurement continue to privilege standardised, quantifiable data and information that can be used for quality standardisation. Despite more than 30 years of developments in patient-centred and then person-centred care, the focus on quantitative measurement has continued to dominate, even though it does little to inform stakeholders about the person-centredness of a health system.

The person-centred care movement is not new in health care and there are some who would argue that other approaches, such as relationship-centred care, have superseded person-centredness.³ The lack of concept clarification and theory-driven methodologies by researchers in the field has done little to help this situation. This failure has also been reflected in approaches to measurement and evaluation. The paper by Cribb⁴ in this issue of the *Journal of Health Services Research & Policy* highlights this problem precisely, that is, the interchangeable use of patient- and person-centred care and a lack of definition of either!⁴

In 2017, Dewing and McCormack⁵ highlighted the problem of researchers evaluating person-centredness without defining what they mean. After more than 20 years of

research in this field, including the publication of concepts, models, theories and frameworks, it is unacceptable not to present a clear definition as a basis of an evaluation methodology.

This lack of precision carries on through the focus on person-centred care as an isolated activity associated with providing care to patients – as if somehow person-centred care practices can be isolated from the context in which they exist. Previously, Laird et al.⁶ argued that the majority of patients experience ‘person-centred moments’ only and few experience ‘person-centred care’. Their research highlighted the inconsistencies that exist in and between different practitioners/staff in providing care, influenced by a variety of cultural and contextual factors in different care settings. Key issues highlighted include how work is organised, what practice is prioritised and privileged, leadership practices and multi-disciplinary decision-making.

Evaluating person-centred care as a specific intervention or group of interventions, without understanding the impact of these cultural and contextual factors, does little to inform the quality of a service. Indeed, measuring person-centred care ignores a central tenet of this approach, that is, the provision of person-centred care is predicated on the existence of a person-centred culture – a culture that is developed and sustained by person-centred staff and supported by person-centred organisational values and systems. Person-centred care can only happen if there are cultures in place in care settings that enable staff to experience person-centredness and work in a person-centred way. With a focus on culture, Dewing et al.⁷ adopted the following definition of person-centredness:

[A]n approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.^{7(p3)}

This definition is relationship-orientated but includes *all* relationships in any health care situation or context. The focus on healthfulness is consistent with contemporary theories of well-being and wellness as health

goals and reflects the diversity of relationships that people experience. Effective cultures have clearly articulated and shared values and so this definition is also clear about the kinds of values that are important in a person-centred culture. To capture the complexity of a person-centred care outcome, it is essential that these influencing cultural factors are also considered in measurement and evaluation frameworks. To not do so only serves to ‘blame’ individual staff for not being person-centred in their care practices without recognising organisational responsibilities and reinforcing a culture of control rather than improvement.

These measurement problems also persist in the development of Patient-centred Outcome Measures (PCOMs). The advancement of PCOMs in health care is to be welcomed, as it represents an attempt at embracing all dimensions of clinical outcome assessment by placing ‘patients, their families and carers at the heart of decisions concerning the most valuable criteria in health assessment, rather than leaving assessments solely to clinicians’.^{8(p7)} More recently, Bradshaw et al.⁹ describe PCOMs as ‘*Person-centred Outcome Measures*’ (my emphasis) without any clear definition or description of what is meant by person-centred as opposed to patient-centred. The development of PCOMs needs to extend far beyond a narrow perspective of pre-determined indicators of clinical effectiveness – even if those indicators have been informed by the voice of patients, families and carers as promoted by IPPOSI.⁸ These standardised indicators can never truly reflect an individual’s experience of a care experience or a health system. For, as Callaghan¹⁰ articulates:

One of the difficulties in dealing with anything related to human experience is caused by no two people being exactly alike. There is so much that we have in common that we are inclined to imagine everyone is the same. Everybody is not. That which has meaning for one person may have none for another. Something of immense significance for one will mean little or nothing to another. The basic axiom is that each person is an individual and as such, a unique entity. This must never be forgotten in our attempts at self-awareness or in our dealings with others.^{10(p21)}

Of course, it is unrealistic for every aspect of a person’s experience to be individually evaluated and accounted for at an individual level, as there is a need to quantify some aspects of experience in health care. However, the obsession with quantification, standardisation and generalising experience needs to be challenged if we are to evaluate genuine person-centred care and cultures. As Miles and Asbridge¹¹ argue:

[W]hen the indicated pharmacological and technical interventions have been instituted, it cannot be realistically

concluded that this is all there is to do and that all of the other manifestations of the illness are somehow ‘someone else’s concern’ and not that of the attending clinicians.^{11(p2)}

Taking account of individual experience alongside the measurement of clinical effectiveness is not new and there are many models of such practices in existence that rely on the use of a variety of qualitative methods. Researchers globally have been engaged in this work over many years, and Dewing et al.⁷ and McCormack et al.¹² have described the models in some detail.

We are, of course, concerned with rigour, in the same way as any evaluator using any methodology. It is always interesting to me that rigour in the use of quantitative data is assumed, while in qualitative methods it has to be defended. We need to respect the integrity of both traditions, recognising their epistemological and ontological foundations, their respective use and usefulness, as well as the knowledge, skills and expertise needed to engage in operationalising the different methodologies and methods.

There is an urgent need to demonstrate the value of person-centred cultures to health care organisations and the significance of person-centred outcomes for patients, families, carers and staff. To do that we need to be clear about our concepts and embrace theory-driven evaluation designs that fully embrace mixed-methodologies and capture the diversity of experiences among all stakeholders, as well as demonstrating effectiveness. The more we are able to see, the better we get at knowing where to look!

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Brendan McCormack 

*School of Health Sciences, Queen Margaret University
EdinburghRINGGOLD, Musselburgh, UK
Email: bmccormack@qmu.ac.uk*