LEADERSHIP

A wide vocabulary for person-centred care

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Many different words and phrases are used to describe healthcare that treats patients as people. Do terms such as 'person centred', 'patient centred', 'people centred' and 'personalised' mean broadly the same thing or do they refer to distinct concepts? Should we prefer one over the others? In this essay, we set out the value and limitations of some of the different terms used to describe what we broadly refer to as 'person-centred care'. We offer a critical conceptual analysis of the most commonly used words and phrases in this domain, exploring how they differ from, and relate to, one another. We argue that there is value in retaining a wide vocabulary: the distinctive emphasis and connotations of different terms allow us to communicate about this multifaceted area of research and practice with nuance and context sensitivity.

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A wide vocabulary for person-centred care

Person centred, patient centred, people centred, personalised: navigating the language of person centredness can feel like a hazardous exercise. Do these terms mean broadly the same thing or do they refer to distinct concepts? Should we prefer one over the others? The matter is complicated by inconsistencies in contemporary scholarship and practice: some researchers and practitioners use terms broadly interchangeably, whereas others argue that they should be distinguished. Amay stick to a preferred term, with some arguing that we should exclusively use a particular designation.

In this essay, we set out the value and limitations of some of the most commonly used terms used to describe healthcare that treats patients as people. We argue that there is value in retaining a wide vocabulary: the distinctive emphasis and connotations of different words allow us to communicate about this multifaceted area of research and practice with nuance and context sensitivity.

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Using precise language can help ensure that, and check whether, the way services are described corresponds to their actual features.

It is difficult to characterise the object of our inquiry without using the language and terms that we go on to analyse but, broadly, we are concerned with healthcare that treats a patient as a whole person, with interests and commitments beyond narrow biomedical concerns. We use 'person centred,' which we consider to be the broadest of the most common terms, to refer to this set of approaches; this is one of the terms that we discuss, and it carries connotations of its own, but we prefer not to introduce another term into an already-crowded field.

Person centred

The language of 'person-centred' care has a long and established pedigree, with origins in psychologist Carl Rogers' person-centred therapeutic approach. ⁵ Rogers argued that psychotherapists should see and value clients in all aspects of their humanity, not only their presenting problems or diagnoses, to help them to connect with their values and realise their full potential. This emphasis on seeing the patient as a whole person, with a full emotional, personal and social life outside of the clinical encounter, remains central to person-centred approaches to healthcare. ^{6–8} The terminology 'person centred' reflects and indicates a departure from healthcare focusing only on illness and disease, or technologies and therapies. Instead, it sees patients as people with emotional as well as physical needs and resources, as well as diverse interests, values and capabilities, who exist in rich social and personal contexts.

The language of person centredness aligns closely to the idea of a 'biopsychosocial' approach to healthcare. This captures the idea that social and psychological factors can cause and shape the presentation and experience of disease, and can affect how people respond to, and engage with, treatment and management. Not taking the broader context into account risks clinical failings, such as missed diagnoses or avoidable use of ineffective treatment strategies, alongside moral or social failings, such as insensitivity and offence. Thus, person centredness can be seen to be partly, or even largely, in service of traditional biomedical ends. However, such an emphasis can obscure the tensions between person-centred and biomedical approaches. Centring 'persons' rather than pathologies or clinical endpoints involves recognising that healthcare can fail to do what is best for patients, even when it generates clinically successful outcomes.

The generality of the epithet 'person centred' means that it can be used to highlight the personhood of people involved in healthcare other than the patients. That is, it can act as a reminder that doctors, nurses, family members and anyone else involved in or affected by

healthcare are all 'persons' too, and that healthcare decision making can, and often should, take into account their capacities, needs, wellbeing and wider social contexts. By the same measure, however, the generality of 'person centred' means that it lacks specificity compared with other terms, such as patient centred, family centred, relationship centred, which identify a more definite target.

Patient centred

The term 'patient centred' also has a long history, being used by psychotherapists Enid and Michael Balint in their development and advocacy of 'patient-centred medicine.' ^{10,11} Many people use 'patient centred' almost interchangeably with 'person centred,' taking it to also be characterised by seeing the patient as a whole person, considering their context, needs and identities. ¹² However, the word 'patient' situates the term firmly with a healthcare space. In this respect, 'patient centred' can fall short of transcending or challenging institutional categories and boundaries. In some areas of medicine, such as vaccination, screening, contraception and sexual health, and pregnancy and childbirth, 'patient' might fail to adequately describe people seeking advice and using services.

The label of 'patient' can carry connotations of relative powerlessness and even moral deficiencies sometimes associated with ill-health, perhaps particularly when applied to members of marginalised groups. However, 'patient centred' can be invoked to emphasise the perspective of the person seeking healthcare in contrast to doctors, healthcare professionals, healthcare institutions, or other actors who have traditionally had the balance of power in their favour in healthcare contexts. Privileging the patient can be seen as a way of counteracting and rejecting the passive role that patients have traditionally been seen as occupying in their medical care. This might involve highlighting the privileged perspective that patients have on their symptoms and experience of disease, the knowledge of their medical history that contributes to clinical diagnosis and decision making, and the capacities and skills that are essential to effective management and treatment.

Focusing on the patient over and above other actors can also be used to emphasise the idea that care pathways and healthcare encounters should be primarily designed around what is best for patients, not just based on what is convenient for institutions and professionals.

People centred

'People centred' is the phrase preferred by the World Health Organization, and reflects an emphasis on individuals being situated within communities, and the need for healthcare services and practices to reflect community values. ¹³ The use of the plural 'people' highlights the importance of cultural and familial context in shaping individuals and their healthcare preferences and needs and can signal efforts to involve communities in healthcare service design. This emphasis might be particularly important when thinking about the ways in which healthcare institutions have systematically overlooked the needs and interests of vulnerable populations.

The term 'people centred' emphasises the need to consider social groupings when thinking about the design and delivery of healthcare and can bring attention to inequalities in access to, and benefit from, health services across population groups. It can also highlight the importance of understanding the social identities of patients, including, for example, membership of religious, ethnic,

racial, linguistic and generational groups, and the implications of these for effective and appropriate care.

Compared with terms such as 'person centred' and 'patient centred,' 'people centred' might underemphasise the individuality and embodied experience of particular people and overlook their relative independence from the social groups of which they are members. Uncritical emphasis on, and appeal to, 'community values' risks masking the substantial heterogeneity that can exist within populations and identity groups. It might problematically obscure situations in which communities and their values undermine the wellbeing and agency of certain individuals or marginalised groups.

Personalisation

The language of 'personalisation' is used increasingly in the context of person centredness. For example, the NHS in England places substantial emphasis on personalisation, seeking to make personalised care 'business as usual across the health and care system', with a 'Comprehensive Model for Personalised Care' and newly established a 'Personalised Care Institute' (www.personalisedcareinstitute.org.uk/) to educate healthcare practitioners in delivering care that involves and engages patients. 14 Personalised care represents a move away from standardised care pathways and inflexible adherence to clinical guidelines, and toward a more tailored approach that recognises that one size does not fit all. The closely related phrase 'personalised medicine' is used to refer to 'stratified' or 'precision' medicine, where data are used to develop care pathways that are tailored to the specific demographics, medical history, prognosis and biomarkers of individual patients. 15 In some cases, this might also include the development and prescription of personalised medication.

Personalised care is often, including in NHS policy, concerned with personal budgets and patients making informed decisions about their care. This focus on healthcare decisions means that personalisation has, in practice, a rather narrower scope than person-centred care is typically taken to have. Healthcare professionals can fail to be person centred in a broader sense, including by acting in uncaring and disrespectful ways, even while exceeding expectations around personalisation, informed consent and shared decision making.

Processes and outcomes

In addition to these terms, which are used to describe and emphasise particular characteristics of healthcare encounters and practices, there are various ways of talking about the kind of thing that they apply to. For example, we can talk about personcentred care, person-centred practice, person-centred medicine, or a person-centred approach (and replace 'person-centred' with any of the other terms discussed). Less attention is paid to the distinction between these labels, but they do have different emphases and connotations.

'Person-centred practice' and 'person-centred medicine' pick out things that healthcare professionals do in the course of their work, which might be characterised by particular intentions, behaviours, processes and the use of certain communication and decision-making tools. However, it is possible for clinicians to do these things but for them not to be experienced as intended by patients; person-centred practice can fail to be person centred in its reception and outcomes. By contrast, 'person-centred care'

can bring the patient into the picture by emphasising the care relationship itself. Although it is possible to care for someone who does not feel cared for, if they are unconscious, for example, 'care' can imply a sensitivity to the experience of the recipient of care. This can highlight considerations of satisfaction with care and patient wellbeing. A 'person-centred approach' might indicate more of an institutional perspective, a planned and deliberate decision to implement particular systems and processes. Whereas medical practice can be person centred without any knowledge of the concept of person centredness or intention to be person centred on the part of those involved, saying that a person or institution is adopting a person-centred approach suggests that they are doing so intentionally.

These distinctions might be subtle and they might not always matter all that much. However, they can sometimes help to draw attention to assumptions about the outcomes of person-centred processes and highlight gaps between intentions and reality in person-centred healthcare. These different emphases might have implications for how person-centred care is identified, measured and assessed, whether using subjective or objective approaches, for example, and whose perspectives or which aspects of healthcare systems to focus on.⁷

A lexicon of person-centred care

We have indicated a variety of different ways of talking about person-centred care and suggested some of the implications and limitations of specific terms. We have selected the most commonly used words and phrases, but similar considerations will apply to other terms, such as 'client-centred' and 'family-centred'. Using a variety of overlapping and related terms to characterise a concept risks creating confusion and misunderstanding. This might suggest that we should stop using some of these terms or to find new terms to replace them with. We do not think that this is the answer.

Maintaining a lexicon of person-centred vocabulary, rather than encouraging or trying to enforce standardised use of one term, also enables nuanced and context sensitive communication. This, we suggest, is particularly important in relation to person-centred care, which comprises multiple different distinct components and which calls for different emphases in different healthcare contexts. The conceptual space described by these terms relates to, and can fail to relate to, a real space of healthcare activities, behaviours and attitudes. It is important to recognise that what is called 'person-centred care' can be neither person centred nor caring, and those navigating and working in this space should remain attentive to hollow claims of person centredness. Scrutinising the language used to describe healthcare practice is one way of holding healthcare institutions to account.

The terms we have discussed each emphasise, and can be used to specifically pick out, important aspects of person-centred care: taking a biopsychosocial approach; seeing patients as experts and active contributors to their care; coproduction of, and equitable access to, healthcare services; and enabling and allowing patients to make informed choices. Perhaps other terms are needed to capture other aspects of person-centred care, such as 'holistic', 'compassionate' and 'relationship-centred care'. To be meaningfully person centred, different healthcare services and contexts might need to emphasise and embody different personcentred characteristics. Having nuanced language to describe these differences has the potential to anticipate or resolve, rather than generate, misunderstandings.

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