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The place of patient-centred care in medical professional culture: a qualitative study

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ABSTRACT

Despite widespread support, the implementation of patient-centred care (PCC) remains a challenge and it is often assumed that further clinical education and culture change are needed. To inform such efforts, we need to know whether the principles underpinning PCC accord with doctors' personal and cultural values. In this chapter, we report the results of a qualitative interview study of clinicians, conducted in order to establish whether PCC emerges in the narratives of Australian doctors, and, if so, how. Our findings suggest that doctors both understand and value the principles underpinning PCC. This suggests that patient-centeredness is part of the professional culture of medicine, and that those wanting to ensure that this patient-centeredness remains an integral part of practice for succeeding generations of doctors might need to focus not as much on education and culture change as on ensuring that there are structures and processes in place to support PCC.

BACKGROUND AND RATIONALE

Patient-centered care (PCC) has been defined in many ways over the past three decades. Core components of patient-centered care have been identified as: respect for patient preferences and values; emotional support; physical comfort; information, communication and education; continuity and transition; co-ordination of care; involvement of the family and friends and access to care (Epstein and Street 2011) . The first of these—respect for patients’ needs and preferences—has emerged as the most consistent element among the many definitions of patient-centered care (Luxford, Safran et al. 2011). This, in turn, entails facilitating patients’ involvement in their own care by sharing information with patients, exploring patients’ perspectives and values, helping with decision-making, facilitating access to care, and enabling patients to follow through with behavioral changes (Epstein, Fiscella et al. 2010).

Advocates of patient-centered care argue that the principles of PCC should not only be understood and respected by practising clinicians, but also that they need to be part of clinical cultures (Luxford, Safran et al. 2011). In this regard, concerns have been raised that the process of enculturation during medical education works against the development of a patient-centred medical culture by encouraging detachment, self-interest and objectivity among students (Coulehan and Williams 2003). The concern is that some students might be able to resist the forces that undermine patient-centeredness, but others adopt a ‘technical’, ‘non-reflective’ (Coulehan and Williams 2003) or even cynically disengaged (White, Kumagai et al. 2009) stance.

While the process of enculturation during clinical training is important, ultimately what matters is whether or not *practising* clinicians inhabit a patient-centred culture. We know that, when asked directly, clinicians tend to espouse patient-centeredness and believe that they themselves engage in patient-centred care, within the bounds of various professional constraints and organisational, personal and patient-derived limitations such as lack of resources and leadership, lack of skill and time, and difficulties in communicating with certain groups of patients (Tufano, Ralston et al. 2008). There is, however, some empirical evidence that health professionals defining patient-centred care actually adopt a model in which professional priorities determine patients’ needs (Gillespie, Florin et al. 2004) and that adopting a patient-centred ideology can threaten clinicians’ sense of status in relation to patients and colleagues (O’Flynn and Britten 2006).

While this research is helpful, it is limited because doctors’ espoused stance towards patient-centred care, whether positive or negative, might not accord with their actual (personal and cultural) values. Similarly, definitions of PCC provided to research participants

might differ from the ways in which patient-centred care is actually understood—which is highly likely given the broad variety of definitions of patient-centred care. An alternative approach, which we pursue in this chapter, is to ask practicing doctors to describe their values in general terms, and then to ‘read for’ themes that might reflect a patient-centred culture (or lack thereof). As part of a qualitative study of clinicians’ values, we therefore, ‘read for’ statements that appeared to be related to patient-centred care, with a view to determining whether and how patient-centeredness played out in our participants’ narratives. We emphasise that we did not ask specifically about patient-centeredness, but rather allowed relevant statements to emerge from the data.

METHOD

In this study, medical doctors associated with the Sydney Medical School were invited to reflect upon the ways in which values matter in their practices and their educational experiences. Interviews were semi-structured, with participants encouraged to reflect on episodes in their careers that had stayed in their minds because of their moral dimensions. They were also asked to talk about specific issues such as the cost of healthcare, the availability of health services, the appropriateness of the medical education program that they had received or were teaching, the place of evidence and research in medical education and practice, and the impact of role models and mentors. Interviews were conducted by a medical doctor and a psychologist, either together or separately. All interviews were anonymised with coded numbers used for each participant. Ethical clearances were obtained from the University of Sydney. We have withheld detailed demographic details of each doctor to protect anonymity. There were seven women and thirteen men. Ages ranged from 28 to 76 (median 49), and years since graduation from three to 52 (median 26). Specialties included general practice, internal medicine, surgery, ophthalmology, radiation oncology, psychiatry, emergency medicine, paediatrics and public health.

Transcripts were thematically coded for statements relating to patient-centeredness. We did not attempt to define patient-centeredness narrowly as our aim was to be inclusive and open to meanings that might not be captured in formal definitions. Any statements that related to knowing patients, respecting patients and involving patients (as individuals or communities) in medical decision-making were therefore included in our analysis. We were interested primarily in patient-centred clinical decision-making, and so we did not read our data for other form of patient-centred care such as emotional and physical support, access and continuity of care. We categorised the emergent themes into more abstract concepts, using constant comparison and reformulation of research questions and theories (Morse

1994). Agreement about themes, codes and categories were reached at regular meetings of the research group.

RESULTS

None of our participants spontaneously used the phrase ‘patient-centred care’ but statements relating to patient-centred care were numerous, and emerged almost invariably when participants were asked for their views about ‘evidence-based medicine’ (EBM). Indeed, questions about evidence-based medicine seemed to trigger responses that were as much about patient-centeredness as they were about evidence. Patient-centeredness was thus very closely related, in our participants’ minds, to medical knowledge, and our participants seemed to recognise two, co-existing and intertwined forms of medical knowledge: bioknowledge—knowledge about the body—draws upon many different forms of observational and experimental (including epidemiological) data, clinical experience and clinical anecdote, and lifeworld knowledge—which is knowledge of the experience of being human, and imbedded in cultural, social and personal contexts (Husserl 1985; Habermas 1992). In such a schema, our participants associated bioknowledge with evidence-based medicine, while lifeworld knowledge (in combination with bioknowledge) was seen as the basis of patient-centred care.

The results are organised as follows: first we demonstrate that, while our participants were advocates of bioknowledge and evidence-based medicine, they recognised its limitations. Next we illustrate the importance to our participants of certain elements of patient-centred care, which took two forms: communicating bioknowledge and balancing bioknowledge with lifeworld knowledge. We conclude by showing that our participants were aware of the challenges associated with the communication aspects of patient-centeredness, but nonetheless expected it of themselves and others.

1. Bioknowledge and evidence-based medicine are important but have their limitations

All of our participants expressed at least some support for bioknowledge and EBM:

P8: Well I think it's one of the great revolutions of medical practice. I think it's truly Copernican in its scope; that is the focus has gone from the doctor in the centre of the universe, to evidence guiding practice ...

Bioknowledge, as encoded in evidence-based medicine, was seen as a powerful validating attribute of medical discourse, and as a necessary qualification to enter the community of medical practitioners:

P11: And so if you want people to come and see us with real or difficult problems, then they're going to have to trust the system, and anything that breaks down that trust is a problem for the profession. In answer to your question about evidence based medicine, I think it makes a valuable contribution to the quality and status of medicine.

But while bioknowledge and EBM were strongly supported by our participants, they also posed problems for many, simply because of probabilistic outputs and the persistent doubt that data derived from epidemiological studies or clinical trials would apply to the care of individual patients.

P3: So I now think ... the pendulum is a little too far the other way, in that people feel a slave to guidelines. And people in clinical trials fulfil a certain profile, and the individual in front of you often does, but sometimes doesn't. And so I find that knowledge of clinical trials tempered by the individual factors, is not an easy equation ...

2. Patient-centeredness in communication is important

In their talk, participants tended to reflect upon the importance of two (related) kinds of patient-centeredness as it relates to decision-making: (a) communicating bioknowledge and (b) balancing bioknowledge with lifeworld knowledge.

(a) Communicating bioknowledge

First, participants emphasised the importance of communicating bioknowledge, in the form of statistics, to patients so that patients were aware of existing data, were cognisant of the limitations of this (or any) data and were more able to participate in shared decision-making.

P10: I think it's fair to tell a patient that these are your options, these are the figures, these are the issues, and each individual circumstance is slightly different.

The process of communicating bioknowledge was, however, acknowledged to be an art in itself:

P5: You don't want to just give people a whole list of statistics because I guess the art is trying to use the evidence or the science, and tailor it to that particular situation.

(b) Balancing bioknowledge with lifeworld knowledge

Without exception, the participants in this study emphasised the importance of incorporating lifeworld knowledge into their clinical decision-making. This included allowing patients to define for themselves what constituted a medical problem and how such problems should be diagnosed and treated. In each example that follows, the key role of doctor-patient and patient-doctor communication is very clear.

P1: You have people come in with menstrual problems in their forties, and they don't know that it's quite normal and it's very common. And it's okay ... to say to them 'well actually ... a lot of people do go through this, it's up to you to what extent that's impairing your quality of life so much that you want to do something about it' – at that point it becomes a medical issue, but it doesn't have to be.

P9: ... it was a lovely woman who had metastatic breast cancer ... I thought she would be suitable for this trial that I was doing of chemotherapy, and I thought in three months, six months or some time, that would happen. And as it turned out, she never had chemotherapy ... because of choice she just chose not to have it ... So it was interesting that I spent a lot of time with her and her family, and talked to her a lot, and put a lot of, effort is not the right word, but it was a lot of thought and stuff.

The goal of incorporating lifeworld knowledge into the clinical encounter was not to replace EBM with lifeworld knowledge, but rather to find some way of balancing the two in clinical decision-making.

P9: I think drawing that EBM picture with the evidence and the person's circumstances and their preferences ... I think that's actually quite a good model. And I think the thing is, the less compelling or clear the high-quality research is, the more influential the patient's values and things become ... and so the more finely balanced that decision, the greater the extent of the person's kind of philosophy and attitudes and things.

3. Patient-centeredness is important, but difficult to achieve

It was, however, recognised that lifeworld knowledge may be simply unattainable in some contexts because of the cultural gap between patient and doctor. P10, an oncologist, described how much easier it was to invoke lifeworld knowledge when dealing with an

educated, English-speaking patient than with someone with whom communication was difficult:

***P10:** ... The other patient I saw was a 79-year-old Indian gentleman, who had a very, very high risk prostate cancer ... Now his English was marginal, his son was interpreting, but his son's understanding wasn't great: 'There's cancer there Doc'. And in the end, I just said 'this is the treatment we recommend. ... And I made the executive decision that if I tried to explain the pros and cons and the issues, far too complex. So occasionally I'll make executive decisions, and do what I think is best.*

It was also recognised that some doctors are better than others at eliciting lifeworld knowledge and incorporating it into their clinical decisions. Some people were seen to be particularly good at learning and deploying bioknowledge/EBM, while others were seen to be more skilled at knowing and understanding their patients, and deploying lifeworld knowledge/patient-centred care.

***P15:** Um, I guess there are people who probably know all the facts and probably all the different chemical pathways in the body, and would probably be able to quote any sort of thing out of a textbook.*

***P9:** ...there was a guy called Dr B, who was a very old world general physician... and had this completely implausible ability to remember the personal details of all his patients ... and it just used to astound me how much he knew about their kind of personal experiences and idiosyncrasies and things.*

Doctors were, however, expected to master and deploy both their bioknowledge and their lifeworld knowledge with skill, relevance and sensitivity, even if they were better at one than the other. Failure to at least make the effort was viewed with severe disapproval.

***P15:** I think you need both. I think everybody has a bit of both, then obviously there are some that lean more one way than the other. And I think they've both got their virtues, you can't really say the perfect person would have more of one feature than the other. People with more science are often good at what they're doing, and the ones with more of an arty background succeed in what they're doing, it's different styles. I don't think I could say one is better than the other.*

***P9:** I remember when I was training there was a particular person that I found particularly annoying ... basically it was somebody who I thought didn't really take their responsibilities very seriously. So with the difficult decision, whereas the appropriate response might have been 'look this is difficult, there are pluses or minuses, your views and values are going to be really important in making this decision, what do you think about it?' That might be the right*

thing to say, but this person would say 'well you tell me what you're going to do.' And I saw it was like a perversion of the shared decision-making model.

DISCUSSION

This study provides insights into the current status of patient-centred medicine, as it relates to patient involvement in decision-making, from the perspective of doctors.

Our participants did not need to be prompted to speak about patient-centred care and, although none used the specific phrase, all described patient-centred values and practices. This suggests that patient-centeredness is part of the professional culture of medicine—that is, it is one of the profession's 'shared basic assumptions...that has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think and feel...' (Schein 1992 p.12). While our participants did not use the phrase 'patient-centred care' this is to be expected as shared cultural understandings are often unstated (Martin 2002).

On reflection, it is not surprising that patient centeredness should be an integral part of medical professional culture. After all, the idea that medicine cannot be reduced simply to appropriate prescribing and good surgical technique is evident from the earliest writings about medicine to the present day. Values-based-based medicine (Fulford 2011), narrative medicine (Charon 2001), culturally competent medicine (Hasnain-Wynia 2006), humanistic medicine (Little 1995), person-centred medicine (Fulford 2011) and a host of others have been proposed as alternatives to a narrow, reductionist approach to medicine. Even patient-centred care itself now has a long history. Michael Balint is believed to have introduced the term in the 1950s (Balint 1957) and it has been in use ever since.

Patient-centred medicine was discussed most frequently in the context of discussions about evidence-based medicine. This suggests that the idea of patient-centeredness is deeply embedded in the culture as part of its epistemic value system and its pragmatically-acquired and applied 'social knowledge' (Hakli 2007). It is interesting to note, however, that evidence-based medicine and patient-centred medicine, while both clearly part of the social knowledge of the medical profession, were viewed by our participants as separate concepts—one based on bioknowledge and the other on lifeworld knowledge. This suggests that, despite EBM's avowed inclusion of patient values, narrative, clinical expertise and so on (Sackett, Straus et al. 2000), EBM has generally preserved its association with epidemiology and biostatistics; qualitative knowledge of preferences and values was set apart. Our participants, despite retaining a narrow definition of EBM, freely and proudly gave lifeworld knowledge a place alongside bioknowledge. This suggests that practising doctors do not view EBM as an exclusive discourse, pitched against other, supposedly inferior, forms of medical knowledge and practice. Viewed this way, it seems that some of the concerns about medical dominance, hegemony and resistance to change (Jones 2004)

might be overly simplistic, for medicine is at once person-centred, culturally-grounded, values-based and reliant on different conceptions of 'evidence'.

Whether and how this understanding and appreciation of patient-centeredness translates into actual practice is a separate question, given that culture refers not only to behaviour but also to what guides behaviour (Alvesson and Sveningsson 2008). But these findings do at least suggest patient-centeredness is already a part of medical culture, and that further education alone may not address whatever gaps exist between culture-in-theory and culture-in-practice. In other words, clinicians already possess the knowledge and values required for patient-centred practise. If it is true that doctors, for the most part, both understand and value patient-centeredness, then it follows that advocates of increased patient-centeredness will need to address organisational and structural barriers to its enactment rather than (just) educating health professionals regarding its merits. Steps will need to be taken not so much to convince doctors to be patient-centred and explain to them what it means, but rather to ensure that they have the resources, support and time to practise it, and recognition for doing so. The fact that what is required are systemic and structural reform, rather than cultural change, is both reassuring and challenging. Reassuring because changing culture is difficult, and challenging because systemic change requires both resources and political will (Braithwaite, Hyde et al. 2010).

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