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Patient empowerment or the emperor's new clothes

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Patient empowerment pervades clinical practice, teaching and research: patients are expected to take control over their illnesses or treatments where possible, and doctors are expected to encourage or 'empower' them to do so. The concept is in tune with a wider political and cultural emphasis on individual choice, and gains scientific justification from psychological research and theory that attests to the superiority of ways of coping with challenges—including illness or treatment—that exert control over the challenge.[1] The validity of the view that patients should be empowered to take control and make choices is therefore widely assumed to be unassailable.

Nevertheless, patient empowerment sits uncomfortably with other current medical ideologies, in particular evidence-based medicine.[2] Moreover it is, in reality, constrained by organizational, clinical or economic factors. The scientific basis for the importance of choice and control is also weaker than it first appears. Although controlled studies of empowerment—for example, arranging for patients to choose the nature or timing of treatment, or teaching them 'coping skills'—do often favour intervention groups,[1] effects are variable; sometimes they are transient or favour lack of choice. Moreover, whereas it is normally *assumed* that such interventions enhance feelings of choice or control, researchers have rarely demonstrated that they do. In a study of treatment choice in breast cancer, even though patients of surgeons who offered choice were happier, choice was not the critical factor.[3]

Because of these contradictions and ambiguities, the concept of empowerment needs to be more closely examined than it has been. The term empowerment purports to describe the positivity of patients' experience of involvement in managing illness. Therefore the validity of the concept should be tested by studying the experience of patients who have been empowered.

PATIENTS' PERSPECTIVE ON BEING 'EMPOWERED'

Since Ingelfinger[4] described, nearly a quarter-century ago, his own despair at being given responsibility for treatment decisions about his cancer, there has been little evidence that most patients seek control or choice,[5] and some evidence that they do not.[6] Being ill reduces the importance that people attach to control.[7] More recently, research has begun directly to examine patients' experience of innovations in care that have implemented empowerment. Although it has not yet surveyed the full range of such innovations, the results of intensive study of several that affect important areas of routine patient care are incompatible with the assumption that patients generally seek empowerment or that it routinely serves their interests.

Involving patients in treatment decisions

Being asked to make decisions about treatment options is the paradigmatic way of being empowered. Therefore, increasingly, patients are given information in the belief that this will enable informed choices. However, detailed studies of the ways that patients with cancer use information have proved inconsistent with this belief. Patients value being given information as a way of building relationships with clinicians and maintaining hope—not as a basis for decision-making.[8,9] Researchers have also generally neglected to ask whether patients who are encouraged to make treatment choices regard themselves as exercising choice. An exception was an interview study of women making treatment decisions about ovarian cancer.[10] Whereas most felt that they had made a *decision*, they felt that they had no *choice*. To the patients, treatment decision-making simply meant coming to terms with the disease and acquiescing to the recommendations of the doctor, who they thought knew the right treatment.

Giving patients control over treatment

In practice, patients are still rarely invited to take full control over aspects of treatment. However, one recent and influential innovation is widely regarded as a paradigmatic way in which this can be achieved. 'Patient-controlled analgesia' (PCA) is a system whereby postoperative patients press a button that, subject to maximum dosages and lock-out periods, causes an electronically controlled pump to inject an opioid into a vein. Although it is understood clinically as a way for patients to control their own analgesia, this change in postoperative pain management

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became widespread before patients' views were discovered. Upon being interviewed about their experience, only one of twenty-six patients who had used PCA made spontaneous mentioned of being in control.[11,12] Control was simply not relevant to them; being pain-free and feeling safe were. As a patient explained, when prompted about control, 'when you're in pain, you don't care whether you're in control'.[11] In fact, concerns about overdosing and side-effects, mistrust of technology and ambivalent attitudes to avoiding pain all *restricted* patients' control. Of course, when patients using PCA were given questionnaires to rate their degree of control over pain, most rated it highly—reflecting their acceptance of what they had been told.[13] As another patient explained 'You're in control. That's the idea of it isn't it?'[11] Patients liked PCA because it freed them from the need to 'bother' nurses with their requests for analgesia. That is, an intervention, professionally regarded as empowering, disempowered patients by inhibiting assertion of their own needs from clinical staff.

Coping skills training

'Coping skills' are now widely taught to patients with problems as diverse as motorneuron disease and alcohol dependence.[14,15] By learning such skills, patients are regarded as changing from sufferers from their disease into managers of it. Coping skills training has been applied for several decades to patients with chronic pain in pain-management programmes. These have the explicit function of transferring responsibility to patients for a symptom that doctors cannot treat. Patients are taught to tolerate their pain and to accept that medical treatment will not remove it. Language is important here. The term pain-management explicitly promotes the patient from sufferer to manager of the pain.

Very rarely, however, have researchers asked patients about their experience of these procedures. Peerbhoy *et al.*[16] used coping skills training to encourage arthroplasty patients to be, and to feel, involved in their care and recovery. Exceptionally, the researcher audio-recorded her dialogue with the patients so that their reaction could be analysed. This showed that patients did not use the coping skills to exercise control over their recovery. Instead, they interpreted the encouragement to be 'involved' as encouragement to fit in with staff's needs and 'cooperate'. Once again, an intervention construed scientifically and clinically as empowering was, more accurately, disempowering.

Encouraging positive attitudes in patients

The concept of fighting spirit has guided psychosomatic research in cancer since the claim that patients who 'fought' their breast cancer survived longer than others who acquiesced.[17] Recent more reliable measurement of 'fighting' in a larger cohort yielded no evidence for its benefits.[18] Fighting is central to an influential form of psychotherapy for patients with cancer[19] and is often encouraged by clinical staff. However, what patients mean when they speak of fighting, and what they perceive clinicians and others to encourage when they urge fighting, is not resistance to the disease but suppression of expressions of emotional distress.[20] Because emotional disclosure is a way that individuals assert their own needs from others, fighting should therefore more accurately be regarded as disempowering than empowering. Besides, whether fighting is directed against the emotional reaction or the disease, it is often unrealistic in view of the psychological trauma of diagnosis and the very small and controversial amount of variance in prognosis that psychological factors can explain. Being encouraged to fight can even be a burden where it transfers to patients the responsibility for becoming ill and failing to resist the disease.[21]

In the instances that have been studied in detail, patient empowerment was a professional construction: it existed in the minds of clinicians and researchers and did not reflect patients' experience. Moreover, the evidence showed that 'patient empowerment' can be disempowering and can impair patients' care. Even though patients seem not to embrace choice, control or coping, the routine use of such language in healthcare is dangerous. Clinical staff, managers and researchers who use it begin to regard patients as responsible for aspects of care that those staff and managers have previously accepted as their own responsibility. For instance, the nurse who regards a patient as empowered by PCA to control his analgesia is less likely to look for—or believe—evidence that the patient is in pain.[11] The doctor who regards a patient as 'fighting' cancer may be insensitive to the patient's need for support.

It should not be surprising that the concept of empowerment does not withstand critical appraisal. Although the language of empowerment is so prevalent that it seems natural, a slight change of perspective demonstrates the implausibility of its propositions. Whereas it has become commonplace to praise patients' efforts to cope with their lung cancer, AIDS or renal failure, it would still be regarded as unreasonable to encourage patients to cope with their lungs, immune system or kidneys. The language of empowerment is sufficiently fluid to mask palpable absurdities. It can even extend to coping with, or controlling, sensations or emotions. Although it would be regarded as absurd to urge someone to fight feeling hurt, or to defeat being unhappy, the slogans 'fight pain' or 'defeat depression' resonate in healthcare.

WHY HAS PATIENT EMPOWERMENT ACHIEVED AXIOMATIC STATUS?

The ascendancy of patient empowerment can therefore not be attributed to patients' aspirations. Similarly, effects on patient outcomes of procedures that have implemented patient empowerment are not large or consistent enough to explain their popularity. For example, PCA only modestly improves analgesia when compared with routine care[22] and has no effect by comparison with routine care that has been improved by simple protocols for pain assessment and analgesia.[23] Communication theory suggests that, when a feature of language becomes 'taken for granted', it should be understood from the perspective of the functions it fulfils for the community of people who use it.[24] It is therefore significant that the areas of clinical care in which patient empowerment is furthest advanced are those which currently most challenge medicine—chronic disease, mental illness, pain and medically unexplained symptoms.

We have shown that the transaction that PCA effects is to transfer responsibility, rather than control, from staff to patients.[25] Arguably, it is popular with staff because it removes a responsibility for their patients' pain that is practically and emotionally burdensome.[25] Whilst these transactions are implicit in PCA, they are explicit in the management of medically unexplained symptoms. Medical treatments are often ineffective for these problems and cannot meet patients' expectations; many doctors dislike these patients.[26] In consultation, doctors tend to resist pressure from patients to take charge of symptom management[27] and medical publications commonly describe patients in ways that indicate their responsibility ('frequent attenders') or even culpability ('difficult patients'). Therefore it is not surprising that new treatments for unexplained symptoms are based on cognitive–behavioural techniques, whereby patients are taught to take responsibility for managing their symptoms.[28]

REDRAWING THE BOUNDARIES OF MEDICAL RESPONSIBILITY

We therefore propose that, when doctors, nurses and managers implement patient empowerment, or even just use the language of empowerment, they are taking part in a redrawing of the boundaries of medical responsibility. That is, to the extent that they can regard patients as empowered, they can regard themselves as being freed from a degree of responsibility for them.

It is usually assumed that the boundary of medical responsibility is a product of science—that doctors do what they have evidence they can do. However, Moynihan and Smith[29] have pointed to the commercial interests and political pressures that extend the boundary, for example by genetic testing and concern with unhealthy lifestyles ('burger-culture'). Our analysis indicates that there is also movement in the opposite direction. In contracting the boundary, the language of patient empowerment clearly connects with the wider political and cultural emphasis on individual autonomy and rights that is helping state institutions to shed the responsibility for individuals that citizens had come to expect. Sociological analysis has long been concerned with the advance of the boundary of medical responsibility,[29] but it has been less concerned with its retraction. Empirical research has neglected both processes. The effect of the political, cultural and professional influences on the expansion and contraction of the boundary of medical responsibility are so important that they should be subjects of empirical scientific study.

CONCLUSION

We therefore suggest that, in imposing patient empowerment on clinical care, medicine unwittingly opposes patients' interests. The accounts of patients' perspective that are currently available suggest that patients do not generally embrace empowerment. In emphasizing research into how to empower patients at the expense of research into what patients feel like when they have been 'empowered', medicine paradoxically continues the tradition of assuming that 'doctor knows best'. Unless the balance of research is reversed, academic and political statements that 'patient empowerment . . . has put patients in charge of their medical destiny',[30] or that 'by offering choice, patients will be given the chance to control their own destiny',[31] will continue to construct a framework for clinical care that obfuscates rather illuminates patients' needs.

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