Debate & Analysis

The emancipation of patients:

a theory whose time has come

INTRODUCTION

A theory can seem unlikely or unwelcome yet make sense of everyday experiences. That patients can be oppressed by doctors and have sought freedom from that oppression — emancipation from it — is such a theory.[1] Oppression is the unjust use of its power by a dominant, stronger group over a weaker group.[2] Here I argue that patients' emancipation is taking place and that recognising this would help free doctors *and* patients from some of the constraints and coercions that hinder medicine from being as humane as doctors' talents and good motives should ensure.

THE BIRTH OF PATIENT EMANCIPATION

Since the late 1950s, some patients and patient groups have opposed policies and practices that they see as against their interests and those of patients like them. At first they acted intuitively, without an overall goal; however, by the late 1980s, the consistency and coherence of their actions created those actions' meaning: they were working towards two primary objectives. The first was for patients to be treated as people whose autonomy and moral agency were respected. The second was for patients to have an equal voice with doctors, both in the individual doctor–patient relationship and in wider discourses about policies and standards at various levels of health care. For individual patients, shared decision making can secure equality and voice.[3] For patients collectively, the representation of their interests and values through the voices of patient activists (advocates or representatives) can work towards securing equality of voice.[4,5] Patient activists' pursuit of these objectives shows that they are engaged in emancipatory work to change the balance of power between doctors and patients. Non-activists, the majority, select and spread activists' ideas, benefitting their successors and activism itself.[6] These ideas and actions are typical of emancipation movements, such as the women's, the anti-slavery, or the civil rights movements.

DIFFERENCES FROM OTHER EMANCIPATION MOVEMENTS

Along with similarities between many other emancipation movements and that of patients, differences stand out. First, doctors are committed to acting for the good of their patients: that is enshrined in their beliefs about their own moral status.[7] Men are not always committed to the good of women, nor white people of black, nor slave owners of slaves. Second, patients recognise that most doctors have good intentions towards them and are grateful for their clinical competence and their help in the vicissitudes of sickness, impairment, and death. But doctors' professional commitment to their high ideals and the excellence of much of their clinical care can obscure their shortcomings from themselves and from patients. Moreover, greater power-holders can be blind to the hardships they inflict on weaker groups and individuals.[8] What doctors see as benign beliefs and actions, patients may see as putting them at unjust disadvantages. Three examples follow.

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Doctors' sense of being different and special

The eminent GP Dr Clare Gerada argues that during their training doctors come to believe that they are special and entirely different from patients: patients become ill but doctors do not. This belief defends them psychologically against their close proximity to sickness and suffering.[9] However, feelings of difference can slip into feelings of superiority; then the more powerful group can behave oppressively towards the weaker. In medicine, feelings of superiority sometimes glimmer through in, for example, the way some doctors speak patronisingly to patients ('hello, my dear', baby talk), disregard what they say, or assign patient-speakers at conferences the worst slots.

Patients notice. They feel they are not being treated 'as people'. They can feel so angry at being patronised that they rebuke the doctor instantly. More commonly, they wait to tell their friends, with distress or with derision, the recourse down the centuries of those treated as inferiors.

Doctors should think about unconscious defence mechanisms; how their effects can be mitigated consciously; and how working environments can be made less stressful and more supportive psychosocially, for themselves, other healthcare professionals, and patients.

Secrecy

Secrecy is a form of power that undermines patients' autonomy. It prevents them from considering and voicing their own interests, responsibilities towards themselves, their dependants, their communities, and their doctors. Much of doctors' secrecy is probably accidental or inadvertent, or propped up by assumptions that patients do not want to know, for example, about the risks of side effects or a lack of up-to-date X-ray equipment. But sometimes, secrecy is so useful, saving doctors time and trouble in explanation and discussion that, even when it is inadvertent, it seems to patients, deceitful. The Quality and Outcomes Framework, in which most patients were not told that their consent to certain courses of clinical action would earn their GPs extra money, exemplified this.[10]

Patients' electronic access to information and online consultation with other patients works against secrecy.[11] Even so, secrecy can act so cogently that it is always potentially oppressive.

Resistance

We all tend to resist changing the way we do things unless they are to our obvious benefit. But when patients and activists

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raise the same issues again and again for years; back up their arguments for change with evidence, often drawn not only from science or social science but also from patients' distress; and cite standards from the medical royal colleges or the General Medical Council, protracted resistance is hard to justify. Yet it took 30 years for patient activist groups to secure unrestricted parental visiting in all children's wards in the UK.[12] Now parents and many staff are unaware that visiting was ever restricted. Today, some doctors oppose patients searching the internet for knowledge and forming or joining e-patient groups.[13] The distinguished doctor Dame Deidre Hine says that resistance seems almost a cultural response in medicine.[14] When doctors resist changes to policies or practices that would support patients' autonomy or voice, they act oppressively. Explanations from patient activists and doctors' own understanding can lift that oppression, but often only after patients have suffered unnecessarily.

THE POSITIVE IMPLICATIONS FOR DOCTORS OF PATIENTS' EMANCIPATION

Emancipation is a political concept with profound ethical implications. Seeing oppression as a consequence of structural factors in wider society, as well as within the medical profession itself, liberates doctors from guilt for the oppressive policies and practices they inherit. That frees them to try to change oppressive elements in their own practice, their peer group's, and their profession's. The theory also:

- lets doctors see the patient component of health care more clearly. 'Ordinary' patients are non-activists; patient activists are patients as well as activists; non-activists and activists hold a range of views, from conservative to progressive, just as doctors do;
- helps doctors choose which of patients' and of managers' interests they should align themselves with, when there is conflict between the two;
- puts into context doctors who introduce new ideas and practices that support patients' autonomy and voice. They can be unpopular with their colleagues at first, but, if those practices result in better clinical or psychosocial outcomes, they can earn respect for their leadership. Medicine is a rational profession, rightly putting a high value on clinical competence, as patients do; and
- shows in what direction new standards will tend to move and by what criteria to judge them. Patient-centred care, for example, has brought measurable improvements to patient care.[15] But it has not aimed to alter the basic power relations between doctors and patients. It is a foothill on the way to a higher mountain.

CONCLUSION

Reality can bring sickness to doctors and turn them into patients. Some doctors' awareness of this, rather than defensive denial of it, may partly account for their willingness to move towards standards that support patients' autonomy and voice. Now doctors and patient activists should think together about how justice and equality between doctors and patients can be strengthened, engendering reciprocal relationships of good feeling and respect.

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