

Debate & Analysis

'Real' patients and 'real' doctors?

Doctors and patient activists in working relationships

INTRODUCTION

Patient activists are usually patients or former patients who seek to improve patient care for other patients, not for themselves. They came into being about 60 years ago when some patients realised that patients' and doctors' perceptions, values, and interests could conflict as well as coincide. From their earliest days, sometimes patient activists, sometimes doctors, have sought each other out to try to reconcile some of the conflicts over standards of care and treatment. They meet variously: one-to-one; in groups of doctors and activists working regularly together for years; and arrangements in between. Doctors and patient activists are alike in many ways and this can help their working relationships.

BOTH WORK FOR PATIENTS' GOOD

Patient activists represent, in the sense of speaking for, patients' clinical, ethical values and their political interests. Sometimes called patient advocates or patient representatives, they are not typical of any category of patients nor a conduit for their views. Individual patients are authoritative judges of their own experiences and outcomes, but they cannot usually speak for other patients' views and judgements because they seldom know what they are. But, in the late 1950s and early 1960s, patients began to form patient activist groups to speak for the interests of patients like themselves. Then, in the mid-1970s, some patient group members began to speak for patients' interests in aspects of patient care that were common to all patients. Patient activists now fall into two broad categories: those who study in detail the clinical and the psychosocial experiences, views, values, and interests of one or of a few categories of patients, for example, with breast cancer or colorectal disease; and those who concentrate on wider, more general, and more abstract aspects of patient care, like patients' consent to treatment or the ethical conduct of clinical research.¹ The categories overlap and some activists belong to both. Many situations and discussions require both kinds of expertise, specialist and generalist.²

Sometimes dismissed as 'self-selected', patient activists choose to study patient care and patients' experiences and views, just as doctors choose to study medicine. Activists, like doctors, come from various

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social backgrounds. The early pioneers devoted themselves, unpaid, to patient activism. Now most have or have had paid employment and other careers. A few are doctors, swimming against their profession's mainstream. All patient activists have to comply with the norms of behaviour in our society to be acceptable to their peers, to health professionals, and to those making appointments to local and national liaison groups, ethics committees, research committees, advisory committees of the medical royal colleges, NHS governance bodies, and government committees.

Patient activists are sometimes criticised for not being 'real' patients. When they are ill or injured or at the onset of disability and in consequence are in clinical relationships with doctors, they feel the same doubts, anxieties, and vulnerabilities as other patients. But when they are in working relationships with doctors, they have other feelings, draw on impersonal knowledge, hone their arguments carefully, and rely on different social skills. Doctors are just the same. They do doctoring, but some also sit on committees, debating policies, contradicting or agreeing with their fellow members. No one supposes that they are not 'real' doctors; their dual role is taken for granted. So, equally, patient activists' dual role is valid.

Patient activists and doctors can approach each other in various ways. Some of the medical royal colleges and faculties have set up doctor-patient activist groups, though others have chosen doctor-lay public groups instead. Patient activist-doctor groups have varying proportions of

activists to doctors. Whatever the group's structure, their members' expertises should be matched to the kind and level of the task. Groups should meet regularly enough for members to develop mutual confidence and trust. Then perspectives can be explained, conflicts identified, evidence and argument adduced, consensus reached, or compromises agreed.³ That can lead to changes in standards at local or national levels.⁴ Ideally, at least one patient activist group would shadow each clinical specialty or subspecialty.⁵ For general practice, patient participation groups give complete cover, with one in every practice. Part of their role is to act as 'critical friends' scrutinising the practice's services.⁶ But both doctors and patients can find combining clinical and working relationships inhibiting.

Just as doctors can rouse feelings of ambivalence in patients, activists can incur doctors' hostility for their challenges — or gratitude for their insights. As one pathologist, reflecting on the group in her college, said:

"We need to work with people who do not doubt our good intentions, but are prepared to tell us things others will not."

BOTH NEED SOURCES OF KNOWLEDGE

Doctors and patient activists both depend on informational and ideological knowledge to guide their actions and explain them to other people. Doctors' sources of knowledge are (mostly) easy for anyone to find: textbooks, general and specialist medical journals, and the medical royal colleges' publications. Patient activists

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ADDRESS FOR CORRESPONDENCE

Charlotte Williamson

Midgley House, Spring Lane, Heslington, York YO10 5DX, UK.

Email: charlottcedwilliamson@gmail.com

as well as doctors can read them. The sources of patient activists' knowledge are scattered, incomplete, and often obscure. Patient activist groups' journals may include critiques of specific patterns of care or treatments and set out the standards they want to see in professional practice instead. Medical journals sometimes publish articles by patients or patient activists. The internet can be useful and can give access to virtual patient groups. But general, comprehensive expositions are hard to find and, like medical writings, sometimes contradictory.

By the late 1980s, however, it became evident that diverse patient activist groups were trying, through their criticisms and pressures for better care, to secure freedom for patients to meet their responsibilities towards their dependents and themselves. Patients wanted standards of treatment and care that gave them more information, more part in decision making, greater respect from health professionals, more choice, and better safety. From these recurrent themes, general or core principles or standards that supported patients' autonomy could be abstracted.⁸ About 10 principles have been identified, varying slightly with their authors. All are liberating, not constricting, supporting patients' autonomous choices, including choosing dependency. The principles give coherence to activists' knowledge and provide criteria for their assessments of policies and practices.⁹ They give them legitimacy to speak for patients' interests at the general level of the principles because they are derived from patients and are embraced by the majority of them.¹⁰

The influences of patient activism and its general principles on doctors can be subtle and hard to separate from other contemporary pressures and from doctors' own progressive ideas. In 1995, the General Medical Council (GMC) published *Good Medical Practice* under the inspired

leadership of its president, Sir Donald Irvine. *Good Medical Practice* sets out the ethical, clinical, and social bases of medical professionalism. Although it does not mention patients' autonomy or patient activist general principles, the guidance includes 'Give patients the information they want or need ...', 'Respect patients' right to reach decisions with you about their treatment and care', and '... listen to patients, take account of their views ...'.¹¹

Every doctor registered with the GMC has a copy (updated every few years) and the GMC expects them to follow its guidance.¹² Patients are encouraged to expect that doctors will.¹³ So *Good Medical Practice* is a handbook for both doctors and patients. They can check the care and treatment they offer and receive against standards that both can endorse. That is a remarkable instance of harmony between doctors' and patients' political interests and ethical values.

CONCLUSION

Doctor-patient clinical relationships should be based on mutual trust between equals.¹⁴ Doctor-patient activist working relationships can model that trust and equality. They can help create the milieus in which clinical relationships, too, can come to be based on equality of esteem and of voice.

Charlotte Williamson,

Chair, RCGP Patient Liaison Group, London, 1994-1997.

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