

Debate & Analysis

Combining professional and lay knowledge to improve patient care

INTRODUCTION

Doctors and other health professionals acquire knowledge and skills valuable to society during their training. They are also socialised into adopting professional values and norms of behaviour. Lay people lack that unique socialisation and retain the everyday ethical values and norms of their wider society.¹ Although much patient care is judged right and good by both doctors and lay people, disjunctions between professional and lay values and norms can harm and distress patients. Those disjunctions can be hard to bridge. Doctors can find it difficult to notice and accept differences between their values and interests (stakes) and those of lay people, especially those of patients, people in clinical relationships with them. When lay people criticise professional or institutional practice, they usually have to go against the professional (or the managerial) grain; and that requires evidence and careful argument. Here I analyse the sources of knowledge that lay people draw on: general lay knowledge, semi-specialised lay knowledge, and specialised lay knowledge. Each springs from lay people's feelings of disquiet that tell them that some social values or norms may be being breached and that prompt them to seek knowledge that will confirm or refute their concerns. The sensitivity and skill with which lay people do this varies, as do their opportunities for taking action. But the analysis may help clarify some of the issues and inhibitions that hinder doctors and lay people from working together to improve patient care.

GENERAL LAY KNOWLEDGE

Our society holds that humanness, acting as befits a human person,² is a fundamental value. In everyday parlance, humanness means causing no avoidable harm or distress to any sentient being. Patients are vulnerable sentient beings; and patient care is inhumane if it causes them avoidable harm or distress by being harsh or restrictive without being justified by necessities of therapy or of safety. Merely by being lay, lay people can potentially identify aspects of patient care that they feel are oppressive or unkind and that their everyday knowledge tells them can have no therapeutic justification. They can see things that are invisible to professionals and managers, who sometimes seem

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blind to patients' pain or hardship.³ Some examples are: windowless labour rooms for women in childbirth; frosted glass in GPs' waiting rooms that shuts patients off from the view outside; hard, slippery benches; noise droning in from outside a surgery or hospital ward; abrupt receptionists; nurses or doctors addressing older patients by their first names without seeking their permission. To identify obvious instances of avoidably distressing care like these, lay people need only a capacity to feel disturbed by what they see, hear, or read, and the confidence to say so.

SEMI-SPECIALISED LAY KNOWLEDGE

Lay people sometimes see things that surprise or disquiet them, but don't know whether they are justified by therapeutic or safety reasons. Taking flowers to patients in hospital has long been traditional in the UK. But many hospitals now ban them, even in geriatric or long-stay wards. That denies patients pleasure, deprives them of symbols of support and love, removes a pleasant topic of conversation between nurses and patients, and makes wards look bleak. But the justification for the ban, that bacteria in the water in flower vases might harm patients, has no microbiological evidence to support it.⁴ To know that and be able to argue against the ban, lay people have to consult the internet or read general professional journals, such as the *BMJ*, or find out what other hospitals are doing. This kind of knowledge goes beyond general knowledge but is neither esoteric nor highly specialised. Severely restricted visiting times in adult wards can be crowded and tiring for patients, and stressful and inconvenient for visitors. Brief standard appointments for GPs instead of flexible

ones where patients can book a long or a short consultation impose limitations on what patients (and doctors) can say. Members of patient participation groups in general practice, non-executive directors in trusts, and members of the medical royal colleges' lay or patient advisory groups are in good positions to identify such instances and to use semi-specialised knowledge to argue for change.

SPECIALISED LAY KNOWLEDGE

Specialised lay knowledge is a loose body of knowledge, originating largely from patient groups, patients' units of social action, and built up from their disquiet.⁵ It has two aspects, the political and the experiential, easy to separate conceptually but in practice closely entwined.

Politically, patient care is a series of decisions and who makes them matters. Patients are less powerful than doctors or managers whose power (ability to get things done in one's own interests)⁶ lets them disregard patients' interests as patients would define their interests if they knew they were threatened.⁷ But doctors can also use their power to protect patients' interests by ensuring that patients are free to make decisions affecting themselves and their dependants without coercion, that is, autonomously.⁸ Patients' autonomy, including their free choice of dependency, can be upheld by ensuring that policies and practices are consistent with the principles that support that autonomy.⁹ Policies or practices that give patients relevant information, offer shared decision making, keep them safe, enable relatives and friends to support them, and respect them as persons, work towards that end. Lay people can become adept at identifying

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shortcomings in putting those principles into practice and so potentially causing avoidable distress to patients; and can point that out.

Once pointed out, breaches of the principles supporting patients' autonomy can often be recognised by doctors because this political aspect meshes with the principles of medical ethics. Thus, of the four primary medical ethical principles, beneficence, non-maleficence, justice, and respect for patients' autonomy, patients' autonomy has come to be seen as the most important.¹⁰ Patients' concerns and medical ethics evolve over time, probably influencing each other. Lay knowledge tends to be gradually incorporated into medical knowledge and its lay origins forgotten.¹¹

The experiential aspect of specialised lay knowledge is about the details of patients' particular experiences, judgements, and wishes in specific specialties or clinical situations. These experiences are typically collected, studied, articulated, and voiced by actual or virtual patient groups. The Association for Improvements in the Maternity Services, for example, publishes in its journal women's accounts of their good or bad experiences of childbirth (for example, continuity of personal care, respect for their wishes, impersonal routine care, or bullying), analyses of research, critiques of controversial clinical procedures, and articles by sympathetic social scientists, obstetricians, and midwives. Women's freedom to make autonomous decisions, in consultation with their doctors and midwives, about their babies' births is the constant theme.

Some specialties lack dedicated patient groups whose paper or online publications can be consulted, for example, anaesthesia. Lay people may then be unaware of patients' particular concerns but can still apply general principles to specific situations. The validity or representativeness of deductions from single patients' comments, patient groups' criticisms, or surveys of patients' experiences and views, can be judged by this criterion: would they enhance or restrict patients' opportunities to make decisions autonomously? If they would enhance them, they are likely to reflect patients'

values and interests. The experiential and the political meet.

There is nothing to prevent lay people from drawing on these sources of knowledge and developing expertise in using them. But some may be unable to relinquish the political and emotional allegiances derived from the professional or managerial cultures around them.¹² So 'lay' can be a problematic category.

CONCLUSION

Doctors want to give patients humane care. But sometimes they may fail to do this consistently. Lay people who can draw on lay knowledge and can work with doctors to explore each other's reasons for what they want to keep or to change can help make patient care reliably humane, fit for doctors to offer, and for patients to value.

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Provenance

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