Withholding policies from patients restricts their autonomy

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Keeping clinical information about themselves from patients is now considered unacceptable, but transparency about clinical and institutional policies that may affect care is less universal

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Patient autonomy is regarded as a basic value for modern health care in Western countries.¹ The UK regulatory body, the General Medical Council, states that patients must be given enough information to enable them to give informed consent to treatment.² It does not, however, state whether patients must be told about all the procedures or treatments that might help them or only those provided locally.² Yet policies about what information to offer or to withhold are crucial to patients' autonomy. In this article I show the harm that can be caused by withholding information about policies from patients and discuss some of the ethical and political issues.

Importance of policies

Policies set the context, the opportunities and limits, within which clinical care is provided. They shape health professionals' behaviour, sometimes for decades.³ They may be written down as statements of instruction or as guidelines. Or they may be what every member of a clinical service knows informally. Policies are so taken for granted by many health professionals that if patients question some aspect of care, they may simply be told, "It's hospital policy" as a barrier to further questions, discussion, or negotiation.⁴ Policies are part of the situation in which patients find themselves, whether in hospital or in their general practitioner's surgery. So arguably, patients who might be affected by specific policies should be told about them.

This does not always happen because information for patients is contentious. Doctors and patient representatives (patients speaking for the interests of other patients⁵) often hold passionately opposed views about what should be included or excluded.⁶ Each may

see implications in the withholding of policies that the other does not see or thinks unimportant.

Ethical implications

The ethical issues of not disclosing a policy often relate to patient autonomy. Autonomy is variously defined but broadly means self determination and freedom from coercion.¹ Respect for patient autonomy can mean upholding patients' opportunities and abilities to act in accordance with their own values; their responsibilities to themselves, their families, and their communities; and their interests as they define them.⁷ Patient autonomy is supported by principles or general guides to action.^{7,8} Those principles are expressed through rules about what ought to be done in specific situations—that is, in institutional and clinical policies. The principles include information, access, equity, shared decision making, choice, safety, support, representation, redress, and respect.^{7,8} Not informing patients about policies can undermine some of those principles. The following example illustrates this.

The National Blood Service published a leaflet about blood transfusion, current in 2002.⁹ It discussed allogeneic or donor transfusion in detail and mentioned autologous transfusion, the collection of some of the patient's own blood beforehand for use in elective surgery.⁹ Some hospitals did not provide routine autologous transfusion and had a policy of not giving the national leaflet to patients. Autologous blood is safer than allogeneic blood because it cannot transmit viruses like HIV or prions like new variant CJD or cause immunological reactions.^{10,11} Most haematologists would prefer autologous transfusion for themselves.¹² As transfusion is a treatment with risks that patients might think important, they must consent to its possible use before elective surgery.² But if patients are not offered information about alternatives to allogeneic transfusion, shared decision making is vitiated. The doctor knows something relevant—the clinical policy—that the patient does not know.

This bears on respect because withholding information from patients that they arguably ought or need to have denies them equality. Here, it also negated choice because patients could not choose between accepting the risks of allogeneic transfusion, discussing with their doctor other ways of saving or conserving blood, changing to another hospital, or forgoing the elective surgery. Moreover, patients' safety was threatened, and not just by the lack of a routine service.

Some hospitals provided autologous transfusion on request.¹³ But before patients could ask for it, they

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Patients need policy information to make informed decisions about their treatment

had to know that it was a usual procedure. Equity is undermined if a hospital does not offer all patients relevant information because educated, energetic patients are more likely to find out things out independently than disadvantaged patients. Access comes in indirectly. A patient who asks for and is granted something not routinely provided can set a precedent as well as benefiting personally. But even if a request is refused it can alert staff to consider that demand for the future. That can lead to a change in policy or service, so benefiting future patients. Asking for something is one of the few ways individual patients can influence local services or take responsibility for the quality of health care.

Withheld policies

Thus what seems like a simple decision by doctors or managers not to tell patients about a policy can have important ramifications. Withholding some policies prevents patients from knowing what will happen; withholding others prevents them from knowing what will not happen. Some of the withheld policies relate to local idiosyncracies, but others cover widespread practices that are so secret, scarcely any patient or patient representative would know about them. Examples of these that have come to light include the retention of children's organs after postmortem examination, vaginal or rectal examination of anaesthetised patients, and not resuscitate orders.¹⁴⁻¹⁶

Other national policies were (or are) less secret but are nevertheless unsuspected by many patients. These include national guidelines for general practitioners that restrict patients' access to specialist diagnosis until their symptoms match those for established cancers¹⁷ and guidelines that restrict access of some categories of patients to potentially beneficial drugs like statins.¹⁸ Examples of information withheld by some hospitals but not by others include protocols for treatment that give the evidence for and against professionally disputed practices, such as the length of preoperative fasting,¹⁹ and the national leaflets that describe and evaluate women's choices in childbirth.²⁰

The ethical and moral consequences of withholding information on such policies are serious. It hinders patients from playing an autonomous part in their own care; from taking actions that could benefit other patients; and from direct altruism, like donating their child's organs for research or teaching.¹⁴ It also hinders patients from understanding the strengths and limitations of the health service. Withholding denies moral agency to patients, irrespective of the personal or institutional motives. Doctors may withhold policies with good intentions. But though we judge ourselves by our intentions, other people judge us by the effects of our actions on them.²¹

Political implications

Withholding information on policies affects patients both individually and as interest holders in the political arenas of policy making at every level of health care. Individually, the effects relate again to autonomy. Not telling patients about policies that might affect them can deny them self determination. If they are unaware of what might happen to them, they are denied even

Summary points

Healthcare policies may be withheld from patients for clinical or resource reasons

Withholding policies from patients can undermine many aspects of their autonomy

Withholding policies from patients can also repress their political voice

Doctors who offer patients access to policies act ethically

the power of refusal. That is coercion. The control of people is part of all social and institutional life.²² But control through coercion is usually regulated by the law and subject to legal challenge. Hidden coercion is not subject to such safeguards.

Withholding can also disadvantage patients collectively. Patients and patient representatives must be knowledgeable when they speak for patients' interests in policy making groups or arenas.⁵ But patients speaking from their own experiences may be unaware of policies that were withheld from them. Patient representatives, who study patients' experiences and views, may also be unaware. If they do not know about withheld policies, they cannot identify and speak about the possible harms that might result from them. In political language, patients' interests are repressed because they have no voice to speak for them.^{8 23} Hidden power can exert extensive control through its indirect consequences.²⁴

Withheld policies can and do become disclosed, however. Patients or patient representatives may discover withheld policies through chance or through reading professional journals. Or individual doctors may tell them in clinical or working relationships, perhaps as a result of doubts about withholding the information. When patients discover a withheld policy by chance, it may cause distrust of doctors.

What can doctors do?

Doctors can do several things in clinical relationships to support patients' autonomy. These include:

- Offering patients easy access to the institutional and clinical policies and guidelines that might affect them
- Deciding how to make available to patients any policies that are unwritten
- Discussing with patient representatives and groups of patients how best to offer information about policies that might distress or worry patients
- Reviewing the justification for withholding policies that they would seek to circumvent if they or their families were affected by them

It can be difficult to distinguish between policies that are withheld because of doctors' personal or clinical views and those withheld because of shortages of resources or covert rationing. Most healthcare systems, however financed, attempt some sort of rationing and use doctors to carry it out.¹ Some doctors feel that telling patients about policies for rationing would be

doing the state's dirty work. But the opposite is true. To conceal policies that dictate rationing is to collude in the state's silence.

Most doctors wish to practise medicine ethically. Ensuring that patients have access to policies that might affect them is an important aspect of ethical practice.

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Sword swallowing uncertainties

Sword swallowing is said to be dangerous. It certainly was in the Middle Ages, when practitioners in Europe were executed as mystics by the Inquisition. Nowadays there may be fewer than 60 practitioners worldwide, but their activity makes up for the small number. Matty "Blade" Henshaw swallowed a total of 3782 swords in 2003, 50 swords were swallowed simultaneously by 19 individuals at a swallowers' convention in 2002, and a belly dancer has swallowed 11 swords at the same time. With all this going on, even if most swords are blunt, medical mishaps may be expected.

Sword swallowing is not an illusion but, unlike in normal swallowing (when the tongue pushes the bolus up against the palate with the neck in a neutral position), the back of the tongue is pushed forwards and the neck hyperextended. Repeated practice enables suppression of the gag reflex. The pharynx is thrust forward and the cricopharyngeus relaxed. The sword may be passed after deep inspiration with the pharynx filled with air—one practitioner describes "sucking in" rather than swallowing the sword. Once past the pharynx, the lubricated sword is swiftly passed, straightening the distensible and elastic oesophagus. Gravity helps, for the performer is always upright.

The sword passes within millimetres of the heart, aorta, and other vitals but, surprisingly, few deaths related to sword swallowing have been described. A Canadian sword swallower did die, but that was after swallowing an umbrella. Another performer fell from the stage with the sword in situ, and was immediately taken for an x ray but remained unscathed. One amateur attempted to swallow a 90 cm blade while under the influence of alcohol and was said to have lacerated his oesophagus and punctured his lung, but the outcome is not known.

None of these cases is recorded in the medical literature, where sword swallowers are mentioned mainly for their help to early endoscopists. For example, a sword swallower helped Dr Kussmaul of Freiberg to develop a rigid endoscope in 1868 using a straight tube, mirrors, and a gasoline lamp. The only report of a complication in the English medical literature describes a Texan who presented with dysphagia and pain five days after his

performance, when an oesophageal perforation was shown on a contrast swallow.¹ Primary repair was unsuccessful, but the patient recovered after oesophagectomy.

Less severe problems such as haematemesis, mucosal laceration or ulceration, and gastro-oesophageal reflux are mentioned on websites but are not recorded in the medical literature. Their incidence is therefore unknown.

It is also uncertain how often the sword enters the stomach. The longest swallowed sword was 82.5 cm and, even though it was swallowed by a 220 cm (7 foot) giant, the sword must have reached the stomach for the cardia is only about 40 cm from the teeth in normal adults. Interestingly, the Sword Swallowers' Association International defines a sword as being at least 37.5 cm long. The gastric lumen is angled forwards and to the left at the gastro-oesophageal junction, and the body of the stomach then bends round to the right, the degree of angulation being related to body habitus—the angulation being greater in thicker individuals. Some swallowers drink water or eat a heavy meal before a performance to give the distended stomach a more vertical orientation, and radiographic evidence suggests the stomach is sometimes entered. I have found radiographs or video recordings of 14 performers on the web, but in only four asthenic individuals does the sword enter the stomach. The only radiograph in the medical literature that is said to show a sword entering the stomach shows the sword passing through the diaphragm, but it may well be just stretching the intra-abdominal oesophagus proximal to the stomach.

Sword swallowing thus raises at least two uncertainties. What is the incidence of complications, and how often do they stomach it?

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