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Editorials

Developing professional ability to involve patients in their care: pull or push?

The involvement of patients in the decisions about their treatment or care seems an unquestionable advance.[1] There are philosophical and ethical justifications for this.[2] Evidence is also accruing about its benefits—namely, increased satisfaction with care and communication, increased certainty about making the best decision, reduced anxiety levels, and greater adherence to chosen management plans.[3] Some of the practical barriers that limit the greater involvement of patients in clinical practice are also being recognised and addressed,[4] including the wider availability of information to patients, often outside the consultation.[5] Yet patient involvement and informed choices are still not a reality in routine health care. There still appear to be barriers that directly relate to healthcare professionals which must be addressed if patient involvement is indeed to become a wider reality.

Healthcare professionals need to assimilate a number of principles and practices if they are to facilitate patient involvement.[6] Some of these apply more to *global changes in attitudes* and approaches to healthcare provision ("macro" level), and are the fundamental competences which professionals acquire as the platform for their practice.[7] Others relate to their skills in providing care to the hundreds, or perhaps thousands, of patients with whom they interact—that is, the "competences" of practice[7]—and apply to the *process within the consultation* ("micro" level), the way professionals deal with individuals, their needs, concerns, desires, and expectations.

Many of the points raised in this editorial are considered more fully in the supplement on *Engaging Patients in Decisions* which accompanies this issue of *Quality in Health Care*. Free access to the supplement is available on the website at www.qualityhealthcare.com.

At the "macro" level professionals need to appreciate the dilemmas that exist regarding the goals of modern health care. There is an increased focus on standardisation of health care which aims to reduce unacceptable variations in treatments or investigations offered and "consumed". In practice, much of the effort towards this depends on guidelines and protocols which are often rigorously developed. The momentum in this direction has increased recently in the UK with the output from the National Institute for Clinical Excellence and the National Service Frameworks (NSF) for ischaemic heart disease, cervical screening, and others shortly to follow (care of the elderly, management of diabetes).

But there is a tension here. The public health efforts of guidelines and NSFs may result in less flexibility in dealing with individual patients. It may therefore limit the scope for informed choices by the consumers—that is, the patients—and, by implication, they will have less true involvement in the decision making in practice. More informed choices by consumers can result in some opting out of treatment or surveillance programmes.[3] We need to recognise that we may not be able to fulfil the requirements of *both* greater involvement and informed choice at the individual level *and* adherence to guidelines and NSFs at the public health or population level.[8] Awareness and acceptance of the issue is an important first step. Professionals need to arrive at a personal view of how they reconcile this dilemma in their own practice, perhaps even choosing whether to pursue the public health *or* the individually focused approach. They must integrate this personal perspective into their approach to delivery of health care for the patients they see. At the moment practitioners are perhaps more aware of the pressure to meet targets in guidelines and NSFs than they are of the pressures from or desires of patients for more involvement, information, and informed choice. Greater awareness of the latter may depend, at least partly, on acquiring experience and skills in involving patients in clinical decision making—the "micro" level issues.

At the micro level professionals need to acquire or enhance their skills in involving consumers in decisions. The competences required to do this are becoming established[9 10] but, as yet, and as in every other area of health care, gaps between competence and performance still need to be addressed. There are developments now which seek to address these needs of professionals by training. The use of simulated patients to work through scenarios in which participants can experience, observe, and discuss new consulting approaches in a "safe" environment appears to hold promise.[6 11 12] They can also gain confidence in using decision support information that might be appropriate for use in the short consultations of general practice.[13] Both professionals and experienced patient simulators can discuss and explore their reactions to the process of these new consulting approaches. By asking participants to review the process for each scenario undertaken, "reflection-on-action" is promoted.[14 15] The ethical issues are also exposed and brought to the forefront for consideration. Participants address how the skills and techniques may apply in their own practice and how they can accommodate the tension between individual and public health goals. These work based experiential learning

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approaches engender a sense of ownership of the process and are consistent with educational theory.[16]

However, although these training programmes may help professionals to assimilate the philosophy and skills required for involving patients more in decision making, more is still required. Clearly, professionals need to engage with such training and this is not automatic. Motivation for participation in the training is achieved in some healthcare systems by financial incentives or the requirements of revalidation or re-certification. However, a further stimulus should not be neglected—namely, the expectations of patients and patient advocate groups. At present, in the UK at least, a substantial proportion of consumers do not apparently wish to be involved in making choices about their treatment or care,[17] but evidence is also accruing about the benefits of involvement and decision support.[3] There is therefore justification for continued pressure on professionals from patient advocate groups to promote and expect newer consulting approaches. This may prove to be the most crucial influence. At a wider level, it may also be a case study in making explicit the links between patient expectations, professional development requirements, and training programmes. It may provide a model in which professionals identify their needs for continuing professional development directly from the needs of patients and seek new training opportunities.

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Ensuring patients' satisfaction with information about their medicines

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Patients crave information. I am writing this while an inpatient at a London teaching hospital, and the need for information is almost palpable. Patients exchange whispered conversations in which they pass on intelligence (or not) about the ward, its staff, and medical procedures. Visiting time is characterised by families getting cross with the patients because they can't answer detailed questions and "should ask the doctor". Nurses are generally amiable but know little about the individual patients. The pharmacist stalks the end of the beds, reading drug charts while avoiding eye contact and failing to introduce him/herself. Doctors parry questions with the deftness of an Olympic fencer, or give a direct answer which, while factually correct, leaves one yearning for context within which to interpret the facts.

While a patient can be dissatisfied yet cured in hospital (because things are done to the patient), in primary care patients generally look after themselves so they need to be willing partners. The importance of the active cooperation of patients is never more clear than in the case of medicines, the mainstay of treatment in primary care. It has been known since Hippocrates' time that patients do not always take their medicines as directed (sic) by the physician. We now divide these people into intentional and unintentional non-adherers, recognising that, although the end point may be the same, the issue of intentionality is crucial. Why should a patient follow medical advice? Anthropologists have taught us about medical pluralism, a term describing the ways in which patients take advice from more than one specialist or individual. The advice from the doctor is therefore weighed with that of the daughter, the neighbour, the person in the health food shop, and so on. Doctors may believe in science, but that is no reason why patients should.

Patients increasingly require some sort of rationale before following advice. We know that about a third to a half of patients on chronic medication do not follow the advice of their prescribers when it comes to medicine taking. Some of these are doing so unintentionally, perhaps because they cannot remember complicated polypharmacy regimes, and others do so intentionally, perhaps because they have beliefs that medicines are bad, or addictive, or just that the doctor did not understand their problem.[1] The only way we can deal with these problems is to engage with patients and to explain our knowledge and views to their satisfaction. If patients are not satisfied with the amount of information they have received about their medicines, questions remain in their mind and they are more likely to become non-adherent.

How can we know if patients are satisfied with the information they received about their medicines? Help is now at hand in the form of a questionnaire, described by Horne and colleagues in this issue of *Quality in Health Care*.[2] Several questions probe two broad agendas—do patients understand how to take the medicine and what it does, and do they know the risks of taking it? The authors show not just that their instrument (the Satisfaction with Information about Medicines Scale (SIMS)) is reliable, but that it broadly predicts self-reported adherence.

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Non-adherence can extend suffering and allow unnecessary disease progression; it also has significant financial consequences. In the UK the NHS spends approximately £6 billion each year on medicines, of which about 80% is spent in primary care. There are few estimates of the economic consequences of non-adherence, but one of the most quoted estimated that 1.7% of healthcare expenditure in the USA was spent on hospital admissions following non-adherence.[3] Something that helps to predict this event must be of practical use in the health service.

When should we check that patients are satisfied with information? There should not be a single time point, but many, as patients' satisfaction with information could not be expected to be static. They may first receive information in the consultation. Most prescribers could certainly give far more information in the consultation[4]; however, not all would be remembered.[5] When the patient gets home, questions arise as they first use the medicine and integrate it into their daily lives. They may worry whether the medicine is working and whether it is causing side effects.

If patients' satisfaction with information about medicines varies over time, we need to measure it repeatedly and the SIMS should be used accordingly. Prescribers should try it in the surgery. Pharmacists dispensing repeat prescriptions could give it out (and respond to it) routinely when a patient presents with a repeat prescription. Primary care groups in the UK could use it as an audit of their prescribers and pharmacists. It is simple, quick to administer, and easy to record the findings.

The SIMS is not a complete solution. There is debate over what the exact role of information should be in the prescribing relationship; however, all sides agree that more information should be given. At present, when patients take a medicine they give tacit consent to the associated risks—perhaps, as Sharp has argued,[6] we should have informed consent for medicines. Satisfaction with information is just a small part of this large agenda, but it is measurable, achievable, and embodied in an instrument that is easy to use. While we work on the big picture, the SIMS gives us a useful tool for the present day. It is not perfect, but it is here and should be used.

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What changes are needed to provide better standards of stroke care?

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About 4.5 million people worldwide die from stroke each year, and 9 million are estimated to be living with its consequences. One in every three deaths in the UK results from stroke, and it is the single greatest cause of disability in the adult population. Given that the incidence of stroke is estimated to rise by as much as 30% over the next 20 years,[1] it represents a major and ongoing challenge for society. For the people who survive the initial insult, there can be residual difficulties with self-care and mobility, communication, cognition, or emotional wellbeing. Such limitations can bring about major changes in "life", impacting on roles and relationships within the family, social circle, and work. Stroke can clearly be a devastating condition for the individual and his or her family, but dedicated stroke services have been shown to reduce the impact both in terms of mortality and morbidity.

Quite why stroke units work is yet to be clearly established. They rely on a complex combination of skilled staff in a range of professions, acute treatment with thrombolytic agents, early mobilisation, patient motivation, and a host of other factors. Discerning and monitoring the most active ingredients is therefore a difficult task. However, a number of aspects of management[2 3] have been identified as key components of improved care for people with stroke, and the paper by Rudd and colleagues in this issue of *Quality in Health Care*[4] is a timely exploration of how the UK is performing in providing that care.

Rudd *et al* outline a number of areas where there has been improved compliance with standards of best practice in stroke care since the first stage of the national sentinel audit of stroke in 1998. They explore the degree of this improvement and evaluate whether the audit process itself has contributed to the gains. A number of interesting issues are raised in the paper, which hopefully will stimulate ongoing attention to what constitutes "good stroke care" and how best to provide it, as well as what constitutes "good audit" and how best to do it.

Given what we know about aspects of management linked to improved outcomes, it is somewhat depressing to read that the organisation and process of care for people who have a stroke remains geographically variable and less than optimum in many ways. Nevertheless, the paper describes some very positive changes between the two phases of the audit, including:

- an increase in the number of stroke units;
- an increase in the number of consultants specifically responsible for people following a stroke;
- the development of interdisciplinary documentation.

Such structural developments are impressive and, if audit has helped to bring those changes about, all credit must go to healthcare professionals and management for responding positively. There seems little doubt that the efforts to involve relevant stakeholders in developing the audit tool and the wide dissemination of results has contributed to the successes reported. Obtaining strong participant involvement is vital to the success of audit. Johnston *et al*[5] propose a number of success inducing strategies including the introduction of a modern (preferably electronic) system of medical records, the appointment of dedicated staff, and provision of protected time. It

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seems vital that such structural components are in place or audit risks becoming merely an additional task for an already overstretched workforce—which does little to enhance the quality of care.

While audit can go part of the way to ensuring that the best standards of care are delivered, actually *quantifying* many aspects in the care of stroke patients can be problematic. Indeed, it can be difficult to make sure there is even a shared understanding of the definition of some components of a stroke service.[6] The fact that provision of information for patients and relatives is one component of the audit exemplifies this issue. It might seem intuitive in this situation that "more is better", but this is not necessarily the case. Certainly, along with others we have found that the appropriateness, timeliness, and manner of information provision heavily influences whether that information is useful.[7] To be certain that there has been a meaningful improvement in such a process, clarification of the types of information and the manner in which it should be delivered might be required.

Although this study demonstrates an overall improvement in the achievement of a number of standards of care, there is much room for further progress. Less than half of the patients received a formal cognitive assessment, only a quarter had their mood state documented, and the needs of carers were assessed separately in only just over a third of cases. These issues are crucial to the provision of a high quality service. There are also disappointing findings with regard to frequency of team meetings, the attendance of social workers at such meetings, and the in house education of staff. Such factors are usual indicators of good communication and fundamental to truly interdisciplinary teamwork.

There is no doubt that increasing the number of patients who receive the bulk of their care in a dedicated stroke unit is vital if we are to achieve the desired reduction in deaths and disability. All who provide, fund, and use healthcare services would do well to heed this message, made even clearer by Rudd and colleagues.[4] The message is particularly relevant in areas where many patients continue to be cared for in general hospital wards or at home,[8] and in countries (including New Zealand) where few dedicated stroke units even exist. Failure to establish such services, and failure to ensure equitable access to them, is becoming a difficult standpoint to defend.

Finally, despite increased awareness that specialist stroke care improves outcome, investment in stroke research has recently been described as woefully inadequate[9] and many important questions about the best interventions for acute stroke remain. This is also true in rehabilitation where more research is needed into what constitutes the most effective approaches to goal setting, teamwork, and other key components of practice.[10] We agree with Rudd and colleagues that there should be ongoing funding for audit, and that audit can and should be a mechanism for improving what we do. However, it is also important to avoid assumptions that we might know all we need to about which processes to audit. If we listen to people who have had a stroke and their families, we still have a lot to learn about what comprises best practice and indeed "best outcomes".

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Quality of clinical care in general practice

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As quality of care is so high on the agenda of practitioners and policy makers, it is surprising that there are no systematic reviews of studies of the level of quality provided by healthcare services. In this issue of *Quality in Health Care* Seddon and colleagues report a systematic review of studies on the quality of clinical care in general practice in the UK, Australia, and New Zealand.[1]

The authors found that many published reports were methodologically poor and therefore only limited conclusions could be drawn from the findings. Around 90 papers were identified and, not surprisingly, the majority related to management of chronic care and only two related to acute conditions. Practices that took part in the studies were often self-selected, and many of the reports were from single practices. Despite publication of numerous evidence based guidelines in recent years, the authors found that clinical care in general practice consistently failed to meet high standards in all three countries.

Can the findings be assumed to apply to primary care throughout Europe? We can only speculate, but it would be surprising if care in other European countries was found to be substantially better than that revealed in the review. It is more likely that the range of quality would have been wider if a greater number of countries, with diverse healthcare systems and different levels of funding, had been included. The key question in response is: "How can variation be reduced and quality improved?"

The review does not provide information on methods that have been successfully used in general practice in improving quality of care, nor does it indicate whether the drive for monitoring clinical care came from the practices themselves or from other local or national initiatives. Various methods are likely to be used for monitoring the quality of clinical care. However, monitoring must be used in conjunction with a wide variety of methods of implementing change.[2] The recent proposals for improving the use of

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information technology in primary care in the UK will make a wealth of anonymous and aggregated data available for monitoring and reporting aspects of quality of care. Linking variations in care to practices should allow the identification of obstacles to improving quality and therefore inform the choice of strategies to be employed to bring about improvements.

Previous research has identified obstacles to effective health care including clinical, patient related, and resource related categories.[3] This study also showed that the main sources of information used in situations of clinical uncertainty were general practitioner colleagues and hospital doctors. In another survey, promotion and improvement of access to summaries of evidence were suggested as more appropriate methods of encouraging evidence based general practice than teaching about the skills of literature searching and critical appraisal.[4]

The combination of adequate monitoring and targeted implementation strategies implies that healthcare services require well developed systems for managing primary care. In many countries, however, the management of primary care is not a high priority since the vast majority of healthcare spending is accounted for by secondary care. Furthermore, the funding mechanisms in different countries have variable effects on management systems. This is both a problem and an opportunity. The problem is that, until the management of services is adequate, levels of quality are unlikely to improve dramatically. The opportunity is that the diversity in European healthcare systems makes possible evaluations of different systems. If nations were sufficiently motivated, we could determine which systems are associated with higher levels of quality.

Systems of quality assurance have been set up in most countries, but they use different methods which vary from inspection by external appraisers using explicit evidence based criteria at one extreme to informal discussions between colleagues at the other. Recent proposals in the UK have recommended a new framework to support accountability, improve quality, and reduce variations in care. These include the National Institute for Clinical Excellence (NICE) that will provide national guidelines,[5] clinical governance ("a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding of care by creating an environment in which excellence in clinical care will flourish"), and new systems for annual appraisal of all doctors supplemented by regular revalidation at longer intervals. In addition, an inspectorate has been set up and given the title of Commission for Health Improvements.[5]

Almost 20 years ago Sir Donald Irvine (now president of the General Medical Council) pronounced quality of care as the outstanding problem facing general practice.[6] Seddon *et al*[1] have made it clear that this situation remains largely unchanged. If the new UK initiative finally resolves this problem, there will be valuable lessons for the health systems of other countries. If the initiative fails there will still be lessons, although they will not be so valuable.

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Getting journals rapidly to developing countries: opportunities through the internet

For some years it has been the policy of the BMJ Publishing Group to give free subscriptions to journals, including *QHC*, to people working in the developing world. An editorial in *BMJ* sets out the arguments for doing this very clearly.[1] We know that the gap between the rich and poor countries is widening but, while those of us in the developed world have information overload, in some developing countries libraries are empty. However, in practice there have been difficulties—for example, postal services may be very unreliable and getting the printed journal to its destination can be difficult and expensive and, to some places, impossible at times. The marginal costs of sending one year's subscription of *QHC* to Africa is around £25, but the marginal cost of giving access to the electronic edition of *QHC* is close to zero.

As many journals are now on line, the internet provides the opportunity to narrow the information divide. Under the auspices of the WHO, leading medical publishers including the BMJ Publishing Group have agreed to provide free access to electronic versions of journals to people working in developing countries.[2] Access to electronic journals happens at exactly the same time throughout the world. By having access to a range of e-journals, colleagues working in developing health systems will be able to access what is relevant to them and not simply what is provided or what happens to make it through the postal system. Best of all, anyone with electronic access to journals, wherever they work, can participate in debate through the rapid response facility on the web site, something that was not possible in printed journals.

Access to the electronic edition of *QHC* will automatically be provided free to those from countries defined as poor under the human development index by the United Nations (URL http://www.undp.org/hdro/HDI.html/). The BMA and several societies that co-own BMJ Publishing Group journals have funded the installation of Digital Island on all BMJ Publishing Group journal web sites. This clever piece of software recognises where a user is coming from and provides unrestricted access to the whole web site to those from countries we designate. BMJ.com will continue to be free to those in the developing world,

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whatever happens in the developed world. Facilitating access to information should help to encourage informed debate and may even contribute to improvement in health care.

Limited access to the world wide web in some countries is the main barrier. Tens of millions in the USA but only a few thousand in some African countries have access to the web and, compared with the USA, access in Africa may be slow, intermittent (power cuts may happen daily), and relatively expensive (it is often free in the USA). Yet it is likely that access will increase rapidly—for example, currently a million people in India have internet access but this is expected to rise to 40 million within 5 years. Similar increases are expected in Nigeria. Technological developments including better access to radio and the proliferation of satellites will obviate difficulties with telephone access in Africa. Many international organisations including UNESCO, the British government, the World Bank, and the Bill and Melissa Gates Foundation are working towards improving access to information in resource poor countries.

The challenge of all of this is sustainability, and this is a matter that goes beyond providing electronic access to journals. Donors can easily invest and reap rewards of short term success. But enhancing information flow will make no impact on health if projects continue only as long as their funding lasts. Information cannot be separated from the capacity of a healthcare system to work effectively over time. How is it possible to influence the context within which information will flow, the apparently intractable political, economic, and organisational constraints that disable rather than enable information to work for people? Publishers in the rich world have a part to play, and we hope that by making access to *QHC* on line free to those in the developing world, we are making our own small contribution. We hope that this will encourage readers to use the rapid resource facility to discuss and debate issues relevant to quality improvement world wide.

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