Personal paper

Ethics and evidence based medicine

Ian Kerridge, Michael Lowe, David Henry

Evidence based medicine is founded upon an ideal—that decisions about the care of individual patients should involve the "conscientious, explicit and judicious use of current best evidence."[1] Several publications are dedicated to evidence based medicine, and, at an international level, the Cochrane Collaboration has been formed to gather, analyse, and disseminate evidence derived from published research.[2] Several practical approaches to evidence based medicine in clinical decision making have also been described.[3 4]

Evidence based medicine, it is claimed, leads to improvements in clinicians' knowledge, reading habits, and computer literacy; provides a framework for teaching; enables junior team members to contribute to decisions; and allows better communication with patients and more effective use of resources.[5] From an ethical perspective, the strongest arguments in support of evidence based medicine are that it allows the best evaluated methods of health care (and useless or harmful methods) to be identified and enables patients and doctors to make better informed decisions.[5 6]

However, the presence of reliable evidence does not ensure that better decisions will be made. Claims that evidence based medicine offers an improved method of decision making are difficult to evaluate because current practice is so poorly defined. Medical decision making draws upon a broad spectrum of knowledge—including scientific evidence, personal experience, personal biases and values, economic and political considerations, and philosophical principles (such as concern for justice). It is not always clear how practitioners integrate these factors into a final decision, but it seems unlikely that medicine can ever be entirely free of value judgments.

We review ethical concerns associated with evidence based medicine—in particular that it invites a simplistic approach to the role of evidence in medicine, which can be misinterpreted and may not allow for the complexity of clinical decision making.

Summary points

- Evidence based medicine is based on a strong ethical and clinical ideal—that it allows the best evaluated methods of health care to be identified and enables patients and doctors to make better informed decisions
- Evidence based medicine is unable to resolve competing claims of different interest groups
- Collecting sufficient satisfactory evidence raises problems—randomised controlled trials are only possible where there is genuine "therapeutic equipoise"
- Crude application of results of clinical trials to individual care may disadvantage some patients
- Allocating resources on the basis of evidence involves implicit value judgments and could imply that lack of evidence means lack of value

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The philosophical basis

Evidence based medicine represents a practical example of consequentialism—the proposition that the worth of an action can be assessed by the measurement of its consequences. Criticisms of consequentialist philosophies may be considered under three main headings. Firstly, many important outcomes cannot be adequately measured or defined. Secondly, it is often unclear whose interests should be considered in determining outcomes. Thirdly, consequentialism may lead to conclusions that are thought to be unethical from other points of view. These criticisms may equally apply to evidence based medicine.

Immeasurable outcomes

The first philosophical criticism of evidence based medicine is that many important outcomes of treatment cannot be measured. This arises from the fact that evidence based medicine claims to provide a simple, logical process for reasoning and decision making—look at the evidence and decide accordingly. But to make balanced decisions, all the relevant consequences of an action must be considered. Unfortunately, current measures of some outcomes of medical treatment (such as pain) are inadequate; some (such as justice) may not be measurable; and other complex outcomes (such as quality of life) may not even be adequately definable.[7 8]

The philosopher Bernard Williams notes that values which may be easily quantified in economic terms often require comparison with values which are

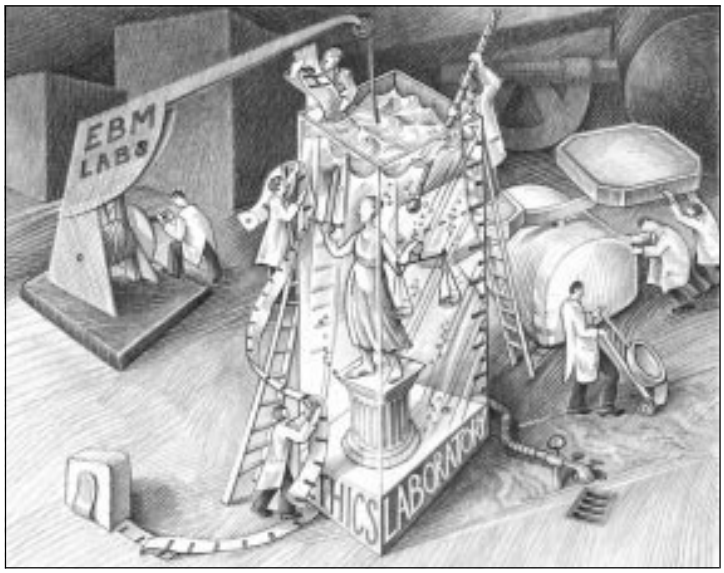
not quantifiable. "Again and again defenders of such values are faced with the dilemma of either refusing to quantify the value in question, in which case it disappears from the sum altogether, or else of trying to attach some quantity to it, in which case they misrepresent what they are about and also usually lose the argument, since the quantified value is not enough to tip the scale."[9] This is particularly the case in medicine, where intangible values such as justice or quality of life are frequently balanced against easily quantified values such as cost or mortality.

Deciding between competing claims

The second philosophical criticism, that it may be impossible to decide between competing claims of different stakeholders, is emphasised by the manner in which patients continue to have little influence over the priorities of research. Evidence based medicine claims to reject the power of expert opinion but it is still mostly doctors who determine research objectives, who interpret research data, and who implement research findings. A number of commentators have called for greater involvement by consumer groups in setting research agendas, but how conflicts between the agendas of the different stakeholders are to be resolved remains unclear.[10 11] Evidence based medicine is unable to address political concerns because the values of different stakeholders, and hence the way in which they interpret evidence, cannot always be made congruent with each other.

At odds with common morality

The third philosophical criticism, that evidence based medicine may lead to activities that seem at odds with common morality, arises from the fact that evidence based medicine assesses interventions solely in terms of evidence of efficacy. An example of the difficulties that may arise from this approach occurs in the field of meta-analysis. Researchers performing meta-analyses are generally urged to search as widely as possible for data and to use unpublished studies if they are methodologically sound. However, valuable research findings may arise from unethically conducted research and data from unpublished studies may not meet the ethical safeguards that are demanded by publishers. In such cases it may be unclear whether results should be used or discarded.



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Most of the discussion of this topic has focused on Nazi experimentation,[12] but there are many more recent examples of unethical research.[13] The *New England Journal of Medicine* has stated that it will not publish results of unethical research, regardless of scientific merit; but what these standards mean in practice is not entirely clear.[13–15] For example, the Gruppo Italianao per lo Studio della Sopravivenza nell Infarto Micardio (GISSI-2) trial, published in the *Lancet* in 1990, did not require the informed consent of trial subjects.[16] Although few present day ethics committees would accept this standard, this study has been widely quoted and included in many meta-analyses. Ethically it seems clear that both researchers and publishers should consider the ethical basis of studies that are included in meta-analysis, but the extent of this obligation remains uncertain.

Collecting evidence

Randomised controlled trials

Proponents of evidence based medicine emphasise the value of some forms of evidence over others, placing particular emphasis upon the results of randomised controlled trials.[17] For example, the United States Preventive Services Taskforce rates the value of evidence from randomised controlled trials as "grade I," evidence from non-randomised trials as "grade II," and evidence from the opinions of respected authorities as "grade III."[18]

Ethical concerns

Randomised controlled trials have the potential to prevent the propagation of worthless treatments and confirm the value of effective treatments. They raise a number of issues that cause ethical concern, including: the selection of subjects, consent, randomisation, the manner in which trials are stopped, and the continuing care of subjects once the trials are complete.

"Therapeutic equipoise"

The administration of randomised controlled trials requires doctors and patients to balance the requirements of several distinct roles—doctors may act simultaneously as physicians and research scientists, and patients as invalids and research subjects. It has been suggested that physicians' moral responsibilities towards their patients are inconsistent with any recommendation that the patients should participate in randomised controlled trials because of this conflict of interest.[19 20] However, it is held that doctors may recommend that their patients participate if they are in a state of "therapeutic equipoise"—that is, there is genuine doubt about the value of different interventions.[21]

Equipoise is not generally a problem in large clinical trials designed to investigate treatments with only moderate effect sizes. Indeed, a major value of randomised controlled trials is that they allow identification of moderate benefits that would otherwise be obscured by bias and random effects.[22] However, equipoise may not be achievable when interventions have very great benefits, or major risks. These interventions

need to be investigated in other ways, such as by reporting clinical observations or through the use of historical controls. Researcher's choice of experimental protocols may therefore be limited by ethical concerns and the gathering of "grade I" or "grade II" evidence may be prohibited by ethical requirements.

Using evidence

Individual care and resource allocation

Clinical trials seem the best basis for clinical decision making. However, compared with other topics in evidence based medicine, the techniques for accurate application of trial results have received scant attention. There is a widely held view that the correct approach is through a comparison of the trial subjects and the population to which the results are to be applied.[23] This is not necessarily so, as the overall results of a trial represent an average effect, and even within the trial population some will experience a greater than average improvement in outcomes, while others may suffer harm.[24 25] Consequently, although crude applications of trial results may on average do more good than harm, they may none the less disadvantage some patients.

Systematic bias

Governments and health funds find the notion of allocating health resources on the basis of evidence attractive.[26] Eddy has suggested that healthcare funds should be required to cover interventions only if there is sufficient evidence that they can be expected to produce their intended effects.[27] The Australian health minister, Dr Michael Wooldridge, who is a strong supporter of evidence based medicine, has adopted a similar position, stating "[we will] pay only for those operations, drugs and treatments that according to available evidence are proved to work."[26]

Given the complexities of the issues surrounding resource allocation, the drive to seek certainty and simplicity at the policy level is understandable. However, the large quantities of trial data required to meet the standards of evidence based medicine are available for relatively few interventions. Evidence based medicine may therefore introduce a systematic bias, resulting in allocation of resources to those treatments for which there is rigorous evidence of effectiveness, or towards those for which there are funds available to show effectiveness (such as new pharmaceutical agents). This may be at the expense of other areas where rigorous evidence does not currently exist or is not attainable (such as palliative care services). Allocating resources on the basis of evidence may therefore involve implicit value judgments, and it may only be a short step from the notion that a therapy is "without substantial evidence" to it being thought to be "without substantial value."[8]

Individual versus population health

Evidence based medicine, as described above, concentrates upon the efficacy of individual treatments. Physicians must not only address the needs of individual patients, but should also be concerned with issues of efficiency and population health.[28] Proponents of evidence based medicine argue that these issues can be resolved by the use of "evidence based purchasing." However, decisions reached rationally at the population level will at times conflict with those made in the interests of the individual. Evidence based medicine does not provide a means to settle such conflicts. Even attempts to replace evidence based medicine with other quantitative methods such as "decision-analysis based medical decision-making" seem unlikely to remove from medicine the need for reasoning that is based on value.[29]

Simplistic solutions

According to Williams, "there is great pressure for research into techniques to make larger ranges of social value commensurable. Some of the effort should rather be devoted to learning—or learning again—how to think intelligently about conflicts of values which are incommensurable."[9] This is particularly the case where it comes to making decisions about allocation of health resources. Those charged with making these decisions are seeking simplistic solutions to inherently complex problems—the danger is that through evidence based medicine we will supply them.

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Framework for analysing risk and safety in clinical medicine

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Adverse events are incidents in which a patient is unintentionally harmed by medical treatment. Awareness while under anaesthetic, deaths during surgery, and missed cases of meningitis are tragic for both patients and staff, and may lead to complaints or litigation. Investigations usually focus on the actions of individual doctors and seldom examine the background to these events.

In a recent case of a patient whose bowel was perforated during surgery, examination of the medical records led to criticism of the surgeon. Only later did it emerge that the operation had been carried out in near darkness because of several equipment and power problems. Adverse events usually originate in a variety of systemic features operating at different levels—the task, the team, the work environment, and the organisation. We present a framework that aims to encompass the many factors influencing clinical practice. It can be used to guide the investigation of incidents, to generate ways of assessing risk, and to focus research on the causes and prevention of adverse outcomes.

Summary points

- Adverse events in which patients are harmed by medical treatment are common
- Investigations which consider only actions or omissions of individual clinicians are incomplete and misleading
- Psychological research shows that liability to error is strongly affected by adverse conditions of work
- These conditions include high workload, inadequate supervision, poor communication, rapid change within an organisation
- A framework of risk factors allows a systematic approach to safety and error reduction

Adverse events

In spite of increased attention to quality, errors and adverse outcomes are still frequent in clinical practice.[1] The risk of iatrogenic injury to patients in acute hospitals remains high, with studies reporting rates of 4-17%.[2–4] A recent American observational study found that 45% of patients experienced some medical mismanagement and 17% suffered events that led to a longer hospital stay or more serious problems.[5]

Even with the advent of clinical audit, comparatively few studies focus directly on the causes of adverse events. Notable exceptions include the confidential inquiries into maternal and perioperative deaths.[6 7] Leape argues that more attention must be paid to psychological and human factors in the nature, mechanisms, and causes of error—particularly the fact that liability to error is strongly affected by the context and conditions of work.[1] Critical incident and organisational analyses of individual cases have illustrated the complexity of the chain of events that may lead to an adverse outcome.[8–10] The root causes may lie in several interlocking factors, such as the use of locums, communication and supervision problems, excessive workload, and training deficiencies. Some fundamental features of a unit, such as poor communication within a team, may be implicated in a range of adverse clinical events.[4]

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The original model for accident assessment was developed for use in complex industrial settings such as offshore drilling platforms

Analysis of accidents

"Human factors" approach

Analyses of accidents in medicine and elsewhere have led to a much broader understanding of accident causation, with less focus on the individual who makes an error and more on pre-existing organisational factors that provide the conditions in which errors occur.[11 12] This "human factors" approach, as it is called, is a hybrid discipline that focuses on the human component within complex sociotechnical systems. The assessment of accidents in large scale systems has acquired a high profile in industry, after such disasters as the fire at King's Cross underground station, Chernobyl, and the Piper Alpha platform. Reason's

model of organisational accidents was originally developed for use in these complex industrial systems, and has now been adapted for medical settings.[11–14] The method is essentially to examine the chain of events that leads to an accident or adverse outcome, consider the actions of those involved, and then, crucially, look further back at the conditions in which staff were working and the organisational context in which the incident occurred.

Active failures

Human decisions and actions play a major part in nearly all accidents. They contribute in two main ways—through active failures and latent failures.[11] Active failures are unsafe acts or omissions committed by those whose actions can have immediate adverse consequences—pilots, air traffic controllers, anaesthetists, surgeons, nurses, etc. The term active failures includes:

- Action slips or failures, such as picking up the wrong syringe
- Cognitive failures, such as memory lapses and mistakes through ignorance or misreading a situation
- "Violations"—deviations from safe operating practices, procedures, or standards.

In contrast with errors, which arise primarily from informational problems (forgetting, inattention, etc), violations are more often associated with motivational problems such as low morale, poor examples from senior staff, and inadequate management generally.

In industry, and to a lesser extent in medicine, defences exist to guard against human error and aid recovery from potential problems. In industry, this might be a failsafe device to shut down a reactor, in medicine the warning sound of a monitor alerting an anaesthetist to falling blood pressure. A full account of these distinctions can be found in Reason's book.[11]

Latent failures

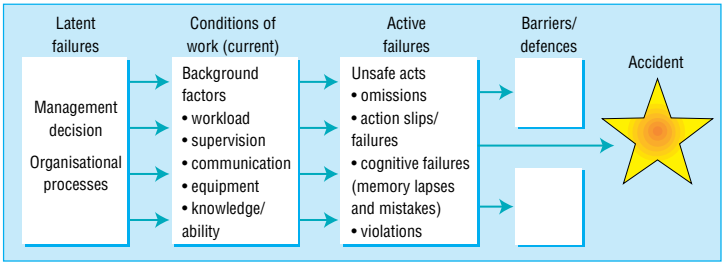
Latent failures stem from fallible decisions, often taken by people not directly involved in the workplace. In medicine, latent failures would be primarily the responsibility of management and of senior clinicians at those times when they are taking decisions on the organisation of their unit. Latent failures provide the conditions in which unsafe acts occur; these work conditions include:

- Heavy workloads
- Inadequate knowledge or experience
- Inadequate supervision
- A stressful environment
- Rapid change within an organisation
- Incompatible goals (for example, conflict between finance and clinical need)
- Inadequate systems of communication
- Inadequate maintenance of equipment and buildings.

These are the factors that influence staff performance and may precipitate errors and affect patient outcomes.

Anatomy of an accident

The figure shows the anatomy of an organisational accident according to this scheme. The accident sequence begins with the negative consequences of management decisions and organisational processes. The latent failures thus created are transmitted along various



Organisational accident model based on work by Reason[12]

organisational and departmental pathways to the workplace (operating theatre, ward) where they create the local conditions that precipitate errors and violations. The model presents the people who are directly involved as the inheritors rather than the instigators of an accident sequence, though this does not necessarily imply that blame is simply shifted "upstream."[12]

Organisational influences in medicine

In the above analysis a hierarchy of factors is involved in the cause, and therefore in the analysis, of adverse outcomes. To understand and prevent adverse events in medicine, it is necessary to delineate the conditions of work and associated latent failures. The oil, chemical, and nuclear industries have developed tools to analyse systematically organisational safety performance.[15–17] Typically, there is a general framework with components specific to that industry. The background conditions that predispose to risk and unsafe practice are directly and routinely monitored to assess not the health of a patient but the health of a unit—the unit's vital signs. While there is certainly interest in organisational influences on medical practice, there is no current framework in medicine that attempts to integrate the whole hierarchy of factors and their components.

Framework for medicine

The framework described below was initially derived from Reason's model of organisational accidents.[11 12] However, we also reviewed the major frameworks in use in the human factors field, such as the socio-technical pyramid of Hurst and Ratcliffe,[16] to ensure that all factors of potential relevance to medicine were included.[15 17 18] Components for the major factors (see box) were primarily derived from medical publications on error, adverse outcomes, and risk management.[1 8–10 13 19 20] The final framework incorporates many features that are of particular importance in medicine, such as patient characteristics, team working, and medicine's unique regulatory and economic context. The box shows the basic framework, and sets out the hierarchy of factors that may influence clinical practice.

Patients and staff as individuals

Clearly the condition from which the patient suffers is the most powerful direct predictor of clinical outcome. However, it has a further importance in this context in that adverse events are more likely when the patient is already seriously ill.[3 21] Other factors, such as the patient's language and personality, may influence communication with staff and, in turn, the likelihood of

Factors that influence clinical practice

Institutional context
- Economic and regulatory context
- National Health Service Executive
- Clinical negligence scheme for trusts

Organisational and management factors
- Financial resources and constraints
- Organisational structure
- Policy standards and goals
- Safety culture and priorities

Work environment
- Staffing levels and skills mix
- Workload and shift patterns
- Design, availability, and maintenance of equipment
- Administrative and managerial support

Team factors
- Verbal communication
- Written communication
- Supervision and seeking help
- Team structure

Individual (staff) factors
- Knowledge and skills
- Motivation
- Physical and mental health

Task factors
- Task design and clarity of structure
- Availability and use of protocols
- Availability and accuracy of test results

Patient characteristics
- Condition (complexity and seriousness)
- Language and communication
- Personality and social factors

an adverse event. A number of staff factors, such as personality, experience, and training, may be influential. The confidence and assurance of staff may be of considerable importance, especially where junior staff are concerned; risk is attached to being nervous and unsure, and also to being overconfident and arrogantly self assured.

Team, organisation, and community

Each staff member is part of a team, both within their unit and in the wider organisation of the hospital or community unit. The way individuals practise and their impact on the patient are constrained and influenced by other members of the team and the way the team members communicate with, support, and supervise each other. The team is affected in turn by management actions and by decisions made at a higher level in the organisation. The team's environment is partly controlled by senior clinicians and managers, although they too are constrained by a variety of circumstances. "Work environment" in our scheme includes such factors as staffing structures and levels, availability and maintenance of equipment, and education and training. The organisation, in turn, is affected by the external environment, including the commercial environment, financial constraints, external regulatory bodies, and the broader economic and political climate.

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Training can reduce adverse events

Specification of components

Each level of analysis can be expanded to provide a more detailed specification of the components of individual major factors. As an example (box), we have expanded the team level to show some of the characteristics that both published reports and analyses of individual events have found to be important in a team's overall performance.[22-24]

Team factors and their components

Verbal communication
- Communication between junior and senior staff
- Communication between professions
- Communication between specialties and departments
- Adequate handover

Written communication
- Legibility and signatures of records
- Adequate management plan
- Availability of records
- Quality of referral and discharge

Supervision and seeking help
- Availability and responsiveness of senior staff
- Clear definitions of responsibility
- Willingness of junior staff to seek help

Structure of team
- Skills mix of team
- Balance of senior and junior staff
- Balance of medical and nursing staff

Applications and development

The framework presented has a number of different uses with regard to the analysis of individual clinical events, the design and validation of risk assessment instruments, and in the design of studies to examine the relation of the many factors affecting clinical practice to the actual outcomes of patient care.

Formalising and extending analysis

Firstly, the framework enables researchers and risk managers to formalise and extend their analysis of adverse outcomes, or indeed of any incident that gives rise to concern. Instead of focusing simply on the actions of the staff involved and on patient characteristics, we can examine the whole gamut of possible influences. While this approach has already been applied productively by using interviews and checklists, much work still needs to be done to standardise procedures of data gathering and analysis and to validate the approach.[9 14 19] The framework can be used to guide this process.

Systematic approach

Secondly, the framework enables a systematic and conceptually driven approach to the development of

organisational risk assessment instruments. Large scale organisational audit instruments cover many of the managerial areas of concern to us, but with comparatively little attention to the daily realities of clinical work and the lower level (but equally important) patient, task, staff, and team characteristics. They can also become increasingly unwieldy, as they seek to cover every managerial process without trying to discern which factors are most important at a clinical level. The framework allows us to focus on key topics and also to consider what the most effective method of assessment might be.

The most important and most difficult problem is assessing the influence of these factors on patient outcome in empirical studies. Research on these broader factors on clinical practice does not exist, although several authors have pointed to the importance of systemic factors in organisational change.[25 26] The extent, for instance, to which team performance and characteristics predict clinical outcomes has seldom been examined in formal studies, though team factors have been strongly implicated in studies of aviation safety and in some preliminary studies in medicine.[24 27]

Error reduction strategies

The ultimate aim of even the most academic and theoretical approach is to help clinicians and managers to improve safety and the overall quality of care. Leape emphasised that safer practice can only come from acknowledging the potential for error and building in error reduction strategies at every stage of clinical practice.[1] The framework enables the examination of the various influences on clinical practice at each stage, which in turn points to interventions and error reduction strategies of appropriate kinds. One reason for the limited impact of many quality and safety initiatives is that they rely on only one level of intervention—for example, staff training or tightening protocols—and give insufficient attention to other factors that influence clinical practice.

Safety needs to be addressed on the basis of a broad assessment of a system's health. Interventions may need to be targeted at several points in the hierarchy, an approach already followed in many industrial settings. Taking such a broad approach to the assessment and management of risk and the improvement of quality may seem difficult, even Utopian, but may be necessary if the level of iatrogenic injury is ever to fall below 4%.

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One hundred years ago

Puffin Island biological station

The days have long gone by when the accomplished naturalist was usually also a physician, yet the majority of medical practitioners still take a general interest in zoology and botany, and will be glad to have their attention called to the modest little report for 1896 and 1897 of the Puffin Island Committee for investigating the fauna and flora of the coast of North Wales, and for promoting the Sea Fisheries. The report, which is edited by Dr Philip J White, gives an account of the useful work which is being carried on with very slender resources by the writer and his friends. The greater part of the papers published in it deal with botanical subjects, but there are some notes on the Welsh fishery exhibits at the Imperial Institute, and a very interesting record of the excavations made by Mr Hughes in Ynys Seiriol (Puffin Island), while Sir William Turner describes a skeleton discovered there, which may perhaps be none other than that of St Seiriol himself. (*BMJ* 1898;ii:742)

Reducing the risk of nosocomial HIV infection in British health workers working overseas: role of post-exposure prophylaxis

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Nosocomial HIV transmission is a particular worry for many doctors, medical students, and nurses who seek work experience in low income countries. Firstly, the prevalence of HIV infection among the patients they care for in poor countries is high. Secondly, these health workers are often relatively inexperienced—their technical skills may not be well practised and hence they are likely to be exposed to blood and other body fluids. Thirdly, many developing countries with a high prevalence of HIV lack the resources to implement universal precautions adequately. Finally, poor or inadequate equipment and facilities are more often encountered overseas and can increase the risks of exposure. These occupational risks are clearly additional to the risks from unprotected sex, for which separate preventive measures apply.

Although the risk of infection per exposure may be low, the cumulative risk with repeat incidents increases and seroconversion does occur.[1] Devastating personal and professional consequences may then ensue, as recently described by Sandy Logie in the *BMJ*.[2] These issues, always a concern but rarely discussed openly, are now to the fore because effective prophylactic treatment after exposure to HIV is available.[3] This is now the standard of care in the United Kingdom but is rarely recommended or available in underdeveloped countries.[4] This raises several important issues for those who go overseas to work, as well as for those who employ them or are their sponsors or educators.

Summary points

- British health workers seeking work experience in underdeveloped countries are at risk from nosocomial transmission of HIV
- Although the risk of infection per exposure may be low, the cumulative risk with repeat incidents increases and seroconversion does occur
- Availability of effective post-exposure prophylaxis raises important moral and legal issues for those who go overseas to work and those who employ, sponsor, or educate them
- Policy guidelines on post-exposure prophylaxis are urgently needed for employers and health workers

Example of the problem

We reviewed nosocomial HIV exposure at a rural district hospital in southern Africa. In this hospital, 25% of patients attending for antenatal care were positive for HIV. Most medical staff are relatively junior doctors from Europe who spend a year or more doing general medical duties, including surgery and obstetrics, that regularly expose them to blood and other body fluids. Few have gained appropriate technical skills before leaving home, and training while working overseas generally consists of practical demonstration by peers.

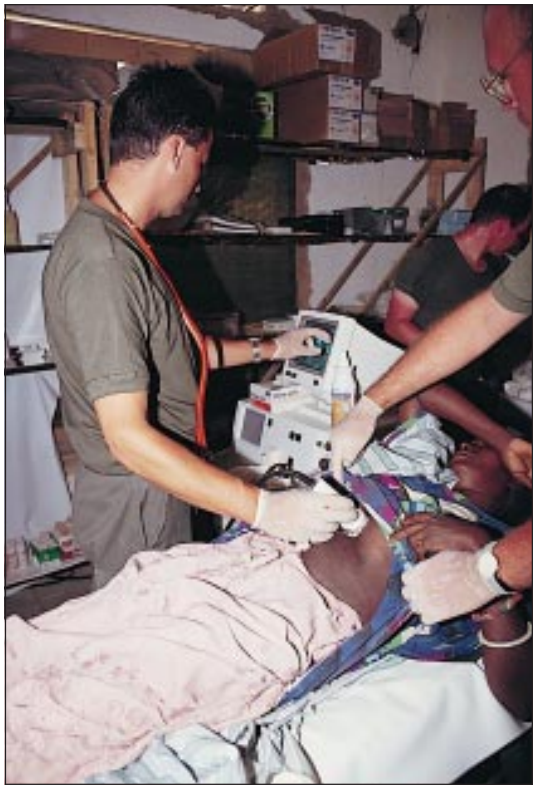
In a recent period of 10 months, five out of eight doctors experienced a needlestick injury while treating a patient infected with HIV. This is equivalent to 0.75 exposures per doctor per year. All incidents were considered severe as each was percutaneous, involved a bloody needle, and drew the health worker's own blood. Three doctors were exposed while using faulty or incorrect equipment for an operation or resuscitation. In two cases, inexperience contributed to the exposures, which occurred during routine operative procedures. All staff took post-exposure prophylaxis and seroconversion did not occur in any.

Extent of the problem

This frequency of exposure is by no means unusual. A group of Dutch doctors working in Africa reported an annual average of five needlestick injuries.[5] In a Zambian district hospital it was estimated that each surgeon experienced three parenteral exposures each year, and that the risk of acquiring HIV infection through work was 1.5% over five years.[6] These may be minimum estimates of risk—needlestick injuries and other exposure to body fluids are under reported and their frequency is higher among less experienced practitioners.

How many British health professionals work in settings where the prevalence of HIV is high, or for how long, is unknown as no formal register is kept. However, by way of example, Liverpool University sends 40-50 medical and dental students a year overseas for elective study. Each year approximately 120 doctors study for the diploma in tropical medicine and hygiene and about 30-40 nurses attend either the tropical medicine for nurses course or the certificate in tropical community medicine and health at the Liverpool School of Tropical Medicine. Most of these nurses and doctors are European graduates who subsequently work in developing countries. Doctors and nurses are also recruited by non-governmental organisations such as Oxfam, Médecins Sans Frontières, Merlin, and Save the Children Fund. Finally, several research bodies such as the Medical Research Council and the Wellcome Trust support expatriate clinical research teams in countries where the prevalence of HIV is high.

From a conservative estimate of one HIV positive needlestick injury per health worker per year in a high



CRISPIN HUGHES/PANOS PICTURES

Nosocomial transmission of HIV is often a worry for health professionals seeking work experience in Third World countries

prevalence area, and a seroconversion risk of three per 1000, one in every 333 health workers would be expected to acquire HIV infection each year through their work.

Emerging issues

Zidovudine alone may reduce needlestick transmission by 81%,[3] and triple therapy with antiretroviral drugs may virtually eliminate the risk of seroconversion. Several issues emerge from the availability of effective prophylactic treatment after exposure to HIV.

Taking responsibility

Are organisations that recruit and employ, or second, health workers under legal and moral obligations to provide cover for occupational hazards such as needlestick injuries? What formal responsibilities do medical schools have for students studying abroad during an elective period? In Britain, anyone exposed to HIV in a work setting would expect to have immediate access to prophylaxis.

Cost of protection

If post-exposure prophylaxis is to be provided, who pays for the drugs? A dose of 1000 mg zidovudine per day for four weeks, a regimen shown to be effective, costs £350.[7] Both Britain and the United States now recommend four weeks of triple therapy for people with high risk exposures (zidovudine (200 mg three times daily), lamivudine (150 mg twice daily), and indinavir (800 mg three times daily)) at a cost of £456.[4 7 8] Full courses of these drugs must be available, stored appropriately, and renewed when expiry dates are reached. Charities and non-governmental organisations, in particular, may be reluctant to take on what could be appreciable extra costs of employment.

Dealing with incidents

Some system, such as an occupational health service, is needed to deal with and report each incident. A baseline serum sample should be stored for medicolegal reasons, and emergency advice, counselling, HIV testing, and drug prophylaxis should be accessible. An appropriate system for offering voluntary counselling and testing of the index case is also required. Because of cost, these services are rarely available in poor countries. What then should be provided? Rapid HIV test kits may be useful in some settings where colleagues can be relied on to be supportive. But what should the single handed practitioner working in relative isolation do?

Equity and access

In those (most) developing countries where post-exposure prophylaxis is not provided or available, and where the non-governmental organisation or research team has made provision for prophylaxis for expatriate staff, what are the responsibilities to local colleagues? Even if it has been decided to cover all project staff (local and expatriate), there will always be a boundary between those healthcare workers who have access to prophylaxis and those who do not. Can this be dealt with fairly without having to provide a full post-exposure prophylaxis service for all healthcare workers in the vicinity?

Developing policy

With little open discussion, few organisations have committed themselves by producing written policy guidelines. Informal arrangements are being widely implemented, but their legal standing is unclear. Most people working overseas have not been given the opportunity to discuss frankly the risks of HIV and consider their own position and possible options in the light of what is available locally. For how long can such an unsatisfactory situation continue?

Recommendations

Open discussion

Awareness of the risk of occupationally acquired HIV infection must be openly discussed with each person who is considering working overseas. Nosocomial transmission of HIV is often perceived as a great threat. Clearly that risk first needs to be put into context. Occupationally acquired HIV infection is relatively uncommon,[1] and health workers are more likely to die in a road accident in developing countries[9] or to acquire HIV from unprotected sexual intercourse. Emphasis can be given to strategies such as better adherence to universal precautions and infection control practices—as far as this is possible given local conditions—and the acquisition of appropriate skills before departure. Some people may then choose not to visit or work in high risk settings, while others may seek to ensure that they have acquired adequate skills and proficiency before they go overseas.

Use of prophylaxis

The point must also be raised that if occupational exposure does occur then the risk of seroconversion can be minimised. The circumstances under which post-exposure prophylaxis could or should be provided overseas needs to be clarified, and the issue of liability should be sorted out. When to use prophylaxis and which regimen to recommend needs to be based on the best available evidence, but cost, drug safety, drug storage requirements, access, and use should also be considered. Extending to expatriate staff working overseas the guidelines on post-exposure prophylaxis that are currently in place in Britain could raise awareness among local health workers of the value of prophylaxis. They could, in turn, lobby national authorities and professional associations for post-exposure prophylaxis to be made available to them.

If post-exposure prophylaxis is not provided by the employer or is not available locally, one strategy would be to purchase or to be given before travel a personal supply of the drugs and to make arrangements for regular renewal if this is feasible. It may also be prudent to discuss what to do if seroconversion does occur. Most people would want to return home in this situation. Valid documentation of the incident is critical in any claim for compensation.

Health professionals already working overseas

The position is more difficult for those already overseas, especially if they have not had much opportunity to discuss and consider the risks of nosocomial HIV. We are aware of considerable anxiety among some of the doctors and nurses we work with overseas. In addition, both of us have had needlestick injuries from HIV infected patients in Africa and have had to consider many of these issues. Again, the important thing is access to up to date and appropriate information about local risks and circumstances, and to be aware of the appropriate course of action to adopt in the event of a needlestick injury. At a minimum this should be discussed during home leave.

Need for guidelines

There is a clear need for realistic, usable guidelines. The intention is not to disincline anyone from working overseas but to promote wide ranging discussion about the very real and constant problem of nosocomial infection in developing countries where HIV prevalence is high. The hope is that all who work overseas are aware and fully briefed about the risks involved and that some form of consensus can be reached about responses that will minimise the risk of HIV seroconversion. Ideally, policy guidelines for both employers and employees will be drawn up. If this paper arouses enough interest and support, we will try to organise the development of guidelines. In the meantime, we will continue to offer ad hoc advice to those who wish to work or are already working overseas.

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Coping with loss

Blindness and loss of other sensory and cognitive functions

Roy G Fitzgerald, Colin Murray Parkes

This is the fifth in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

Series editors: Colin Murray Parkes and Andrew Markus

continued over

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Sensory and cognitive functions enable us to orient ourselves in the world; they make us aware of dangers and rewards; they mediate many sources of pleasure and of pain; and they are the means by which we receive messages from others. Anything that seriously impairs sensory or cognitive function is bound to have profound psychological effects, not only on the person who is affected but also on family, friends, workmates, and caregivers.

Sensory and cognitive losses disable the doctor as well as the patient. When we attempt to communicate with deaf people, their deafness renders us dumb. Blindness in our patients deprives us of the ability to use non-verbal communication. An aphasic person effectively teaches us what it feels like to be deaf. The

Summary points

- Sensory and cognitive defects disable all who come into contact with them, including doctors
- Fear, frustration, and grief are natural reactions in patients and their carers
- Denial of loss commonly impairs rehabilitation
- Anticipatory guidance and support after the loss can reduce long term problems

brain damaged patient makes us feel stupid. We experience the same frustration as they do and some of the same pain.

Problems with communication

The situation is particularly hard when the circumstances demand sensitive and empathic communication, for it is this very subtlety that is most difficult to achieve. The fact that, unlike the patient, we can escape from the frustration—by escaping from the patient—encourages us to do just that. We do our duty, inform them of the help that is available, then leave it all to them. We give up trying to communicate, avoid interaction, and inadvertently indicate that we wish they would stop troubling us. Consequently, it is common for patients with communication defects to feel that they have become a burden to all who meet them. They may be tempted to give up trying to cope with a world that feels unappealing and rejecting.

Yet communication is always possible, and the professional who is willing to take the time and make the effort to communicate with people in this situation can achieve a great deal. Most patients are reassured to know that we understand, even if there is no way in which we can change their situation.

We shall take blindness as our prime example of sensory loss and rely on the research of others to relate this to other types of sensory and cognitive loss. Our examination of the problems of adjusting to blindness stems from a study by one of us of 66 adult Londoners aged 21-65 years who were followed up for an average of five years after being registered as blind.[1–5] This research was supplemented by clinical studies and consultation with service providers for the blind, mainly in the United States, over a period of 25 years.

There are, of course, important differences between the reactions to sensory losses and to cognitive losses, mainly because it requires cognition for a person to understand that a loss has taken place and what this implies. For this reason the two types of loss will be considered separately.

Sensory losses

Onset

Most blind people are not born blind, they become blind.[1] This means that, having learned to rely on their sight in order to recognise and relate to the world, they must now radically revise their basic assumptions about that world. It is not surprising that blindness is usually an overwhelming personal and family catastrophe affecting the patient's mobility, work, personal relationships, and much else.

Although loss of sight is sometimes very gradual, three fifths of the subjects in the London study had less than a year between onset of symptoms and loss of useful vision, with 35% becoming blind in less than two weeks. Loss of hearing tends to be very gradual, and aphasias are more often sudden in onset. Those who experience a gradual onset have more time to prepare themselves for the changes that are occurring, but the changes are easier to ignore.

Reactions to loss of sight

- *Shock* or disbelief ("I didn't believe it was happening to me" or "It's not permanent")
- *Pining* for what is lost—for example, preoccupation with the visual past (83%), longing to see those things that cannot now be seen (97%), high anxiety and episodes of tearfulness (70%); pangs of grief for the visual world triggered by anything that forced the patient to confront the reality of blindness. These experiences were intensely frustrating and evoked feelings of irritability and anger
- *Depression* in 85% of blind subjects continued after the pining and accompanying tearfulness had declined
- *Resolution* often followed one or more turning points associated with increased self esteem and self sufficient acts such as preparing meals for oneself. The depression lifted and crying and social withdrawal diminished

Reaction to sensory losses

The box above shows the approximate sequence of reactions to loss of sight and the frequency with which the phenomena were reported when blindness was established. They resemble the reactions to bereavement and other losses.

Deafness evokes less sympathy than blindness. As the disability becomes established, deaf people go through the same succession of stages of reactions.[6 7] People with aphasia lose their jobs and other skills; they face social isolation similar to that of the deaf person, and their roles within the family undergo profound changes.

Long term adjustment

Progress towards recovery occurred in less than half of the blind subjects studied. Anxiety and depression persisted in half the subjects, and substantial minorities had a lasting decline in self esteem, sleep disturbance, and social withdrawal. A quarter reported excessive weight gain and a third reported episodes of irritability and anger. Persisting pain in the eyes and headache were common and were often thought to be of psychogenic origin. Several young married men had lasting sexual problems, and people who increased their consumption of alcohol or tobacco seldom returned to previous levels.

Sensory and cognitive losses disable the doctor as well as the patient

Comparable difficulties have been reported after other types of sensory loss. In deaf people, psychiatric illness was reported in 19% and high levels of emotional disturbance in another 20%.[8] Much of this was associated with depression. Depression and feelings of worthlessness are also common in people with aphasia and sometimes amount to a "catastrophic reaction" when something happens that brings home the magnitude of the loss.[9]

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Determinants of poor outcome

A major correlate of delayed recovery from loss of vision was persistent denial of blindness: 53% of patients clung to an unrealistic hope of recovery and 58% refused to learn the skills necessary for adjusting to life as a blind person. A third had been to faith healers in the hope of recovering their sight. All too often unrealistic hopes had been kept alive by doctors who, out of a reluctance to upset the patient, pretended that there was still hope of recovery, often by arranging repeated and unnecessary examinations. Denial of blindness correlated with depression and the feeling of helplessness which regularly accompanies depression. It further undermined motivation and deterred efforts towards rehabilitation.

Similarly, deaf people commonly take a long time to accept that there is anything wrong with their hearing, and some never do. This interferes with attempts to persuade them to learn sign language or the other skills that are needed if they are to function effectively. People with a total loss of hearing often persist in attempts to use hearing aids long after these are of any value and may engage in a useless and expensive search for more effective models.

Persisting physical ill health makes additional demands on people at a time when they are already at full stretch. Patients (particularly old people) find it hard to learn how to cope with sensory losses when they already have other health problems.

Preparation for and management of sensory losses

It is usually possible to prepare people for the likelihood that they will lose their sight or hearing, and this will reduce the shock when it happens. In the long run, patients and their families appreciate the doctor being frank about the poor prognosis and the finality of the loss, if that is the case. It is also important for the doctor to be quite clear about the futility of seeking multiple opinions and undertaking wasteful treatments.

People need permission to grieve. They need recognition that this is a normal, natural reaction to loss and not a sign that they are "breaking down."

Members of the family also need opportunities to share their grief as the impact of the patient's condition on their own lives becomes apparent. They need to be involved in the rehabilitation process from the start so that they become part of the rehabilitation team as well as recipients of its care. Failure to do this may bring about the situation in which an anxious wife or husband is undermining the team's effort to help the patient to become autonomous.

It is important for a member of the primary care team to be familiar with the network of rehabilitation services that are available and to ensure that the patient makes full use of these. If, as is often the case, agencies are slow to act, waiting lists are long, and paperwork burdensome, the patient and family must be prepared for this and supported through the waiting.

ADRIANA DORSETT

People with defects and difficulties caused by sensory impairment or cognitive loss may turn away from people who attempt to communicate with them

Warm and affectionate support of confused patients will often relax tension and improve cognitive function

Of particular value are opportunities to meet with veterans, other blind or deaf people who have achieved a reasonable level of adjustment. Many organisations for the blind, for example, have blind or partially sighted people on their staff, and there are mutual help groups run by and for blind people. In the United Kingdom the main organisation for the blind is the Royal National Institute for the Blind (RNIB); in the United States, the National Foundation for the Blind has chapters in each state. Group counselling has been shown to be effective and more of these groups should be established.[10]

If, despite all our efforts, a person fails to meet our expectations of recovery from depression and to achieve a reasonable level of rehabilitation, we should not hesitate to refer them to specialist services.

Cognitive losses

To communicate it is necessary to organise one's thoughts in a coherent way. Many of the problems of communication discussed above also exist when there is disease of or damage to the cerebral cortex, but some additional factors must be considered.

To grieve it is necessary to remember what you have lost. This simple fact explains the relative lack of grief that is found in patients with a severe dementia. Less severe forms of brain damage may, however, give rise to great distress. As long as people have sufficient mental function to realise what they have lost they can be expected to grieve; their grief, however, is likely to take different forms from that of people with intact cognition.

Rapid onset

Cognitive losses of rapid onset (acute confusional states) cause much more distress than the insidious onset of dementia. The experience of disorientation can be very frightening, particularly in an unfamiliar environment. Anxiety itself impairs concentration and judgment, aggravating the symptoms that caused it in the first place. Well meaning nurses and doctors may be seen as strangers who are assaulting the person, and patients may hit out to defend themselves. The thought that we may be losing our mind is so frightening that it is likely to be denied. People will confabulate stories to explain the gaps in their memories and, because their cerebral function is impaired, these stories are often transparently ridiculous.

Care of confused patients

The implications for care are clear. Whenever people are inclined to confusion we should try to maintain their orientation by providing them with reassurance and with simple and familiar cues. If they become confused at night we should turn on the light and talk clearly and reassuringly to them. Warm and affectionate support will often relax tension and improve cognitive function. Although tranquillisers are sometimes needed, they may aggravate confusion and it is wise to keep their use to a minimum and to tail them off as soon as possible.

It is often the partners and caregivers of confused patients, rather than the patient, who need a shoulder to cry on

Progressive cognitive loss

In the more gradually progressive forms of cognitive loss (dementia) people have time to get used to their loss of memory and are less likely to become agitated. Even so, they may get upset if something forcibly brings home to them the fact of their loss of mental ability. Teasing relatives or angry staff who blame patients for being "stupid" may trigger a "catastrophic reaction" in which the patient may rush off, assault people who are to hand, or burst into tears. It is unkind repeatedly to remind brain damaged people of what they have lost in the mistaken idea that they need help to grieve.

Although the dementing patient's grief will usually grow less as his or her condition becomes worse, the same cannot be said of the grief of close family members. It is hard for a husband or wife to accept that the sensitive, considerate, and intelligent partner of 40 years has become forgetful, insensitive, and incapable of the degree of abstract reasoning necessary to see another person's point of view.[11] Many partners and other caregivers will deny the severity of the impairment and interpret the patient's behaviour as wilful or bad. It is often they, rather than the patient, who need a shoulder to cry on. Organisations such as the Alzheimer's Society can do much to educate and support carers.

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A memorable patient

The guiding hand

"What about his little arm, then?" It was some months since I had last seen the child, now seemingly healthy and normal after the grave illness which he had suffered earlier in the year. But his mother, far from expressing the happy thankfulness which I had expected, had something else to say. She pulled up a sleeve, and there at the bend of the elbow was a small scar, healing nicely but still a blemish in that clear infant skin. I looked at it tenderly. "I think it will gradually clear away as he gets older," I said.

It had been a grim 24 hours. Barely conscious on admission, the baby had been vaccinated a couple of weeks previously. At the age of 4 months it was a dangerous time, and we had made a diagnosis of post-vaccinial encephalitis, a rare condition with a high mortality. Steady deterioration followed; a high fever, generalised rigidity and increasingly frequent convulsions were the main features, and there had been no response to our efforts at sedation. The only redeeming feature was a hospital at peace, for it was a Sunday afternoon and in those days there was no visiting.

A moribund baby at death's door, what next? Despairingly, while someone held the tiny arm, I picked up a fold of skin at the bend of the elbow and made a desperate cut, almost at random, with a pair of small sharp scissors, straight through the skin and subcutaneous tissues and finally halfway across a tiny vein whose lumen gaped invitingly before me. This was 1941, and we were not very handy at intravenous therapy in infants, but this was easy and the drip was running in no time at all. Pentothal was our chosen sedative, it had not been tried before, and I could only guess at the dosage. But it must have been right, for in a few minutes the little body relaxed and the convulsions ceased, never to return. Earlier in the day, I had taken a few ounces of blood from two of our trainee nurses, who had been successfully vaccinated three weeks before. The decanted serum followed into the drip, carrying with it, I hoped, all the right antibodies in abundance. From then on, all was plain sailing and the child left hospital a few days later, apparently fully recovered. Perhaps a miracle, and for me the decisive moment was that random lunge with the scissors, guided by luck, providence, and the grace of God.

Over the past 50 odd years since I have occasionally wondered what happened to that little boy. Perhaps he grew up to play for Leeds United or even to bowl for Yorkshire. And I hope that his mother has forgotten about "his little arm" and I have been forgiven.

A formal account of this case was published in *Archives of Disease in Childhood* 1942;17:162-5.

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We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.