

Ethical debate

Sex, drugs, and the invasion of privacy

Patients who are in hospital for long periods may want the same level of privacy they have in their own homes. A clinical team from John Radcliffe Hospital Oxford describes the case of a young man with multiple sclerosis who was suspected of taking cannabis while in hospital for respite care. An ethicist, nurse, doctor, and manager from the Multiple Sclerosis Society give their views on the issue.

Respect for privacy and the case of Mr K

Julian Savulescu, Rachel Marsden, Tony Hope

In Britain, the patient's charter specifies standards of rights and dignity for patients. Little guidance is given about what this means in practice, other than the desirability of providing separate washing and toilet facilities for men and women in hospital. Respect for privacy, however, goes far beyond this. Here we consider the case of Mr K (box).

Hospitals and privacy

Privacy is often at risk in hospital. Patients may feel threatened if staff ask them unnecessarily personal questions or if parts of their bodies are exposed unnecessarily during physical examinations. Confidentiality, one aspect of privacy, can be breached when there is unwarranted access to facts about patients. Yet



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Mr K and the cannabis cake

- Mr K, a former carpenter and artist, is 35 years old. He has multiple sclerosis, which was diagnosed 10 years ago. Mr K has lived with his mother since his wife left him seven years ago. He needs full assistance with activities of daily living, and this is provided by his mother. Respite care is arranged at a rehabilitation hospital
- Mr K's mother asked if her son could smoke cannabis in the rehabilitation hospital. "He has smoked since he was a teenager. I was against it for a long time, but it's one of the few things he can enjoy now. He gets very agitated if he doesn't get his dope, and his spasms are much worse." After consultation with colleagues, the ward sister told Mr K's mother that staff could not knowingly allow him to consume illegal substances on hospital premises
- Mr K was admitted to hospital. Every day his mother brought him a cake, which he ate with relish. One nurse suggested that the cake might contain cannabis. The staff were in a quandary; should they investigate further?

another side of privacy is the freedom to engage—in private—in activities that are important to us.

In this paper, we wish to highlight the importance of privacy in two groups of patients—those admitted to hospital with terminal diseases and chronically ill patients who spend long periods in hospital. For these people the hospital may be home, and they may need enough privacy to engage in important personal relationships and other activities that they value highly.

If hospital is home, attempts should be made to allow patients the same privacy they would enjoy at home. This includes providing space and time that are

their own, so that they can do what they want, free from interference. Sexual relations between consenting adults would not necessarily be precluded. Important limitations to privacy exist, however, and special constraints apply in a hospital (box).

Privacy and the use of illicit drugs

Illegal behaviour raises further issues. Under section 8 of the Misuse of Drugs Act 1971, it is illegal for the occupier of a premises knowingly to permit the consumption of illicit drugs. The “occupier” refers to someone with the power to exclude people from the premises, and in a hospital this probably includes doctors and senior nurses. Health professionals may be in breach of the law if they knowingly allow the consumption of illegal drugs. However, an important difference exists between shutting one’s eyes to an obvious breach of the law and respecting privacy.

Privacy is vitally important. The possibility that a patient may be consuming illegal drugs in hospital should not, by itself, justify invading their privacy, just as the possibility that patients might be using illicit drugs at home does not warrant unlimited access to their private lives.

In the case of Mr K, it would be morally right to ensure that he and his mother are aware of the risks and benefits of using cannabis. But investigating whether the cake contains cannabis would be wrong

Limitations on patients’ privacy in hospital

- Patients should not be free to pursue interests that harm or interfere with others. Private behaviour should not become public in a way that seriously offends others or incites others to break the law
- Patients generally should not be free to pursue interests that cause serious harm to themselves
- Provision of private space and time must be consistent with the proper delivery of health care and must not put an excessive burden on the available resources

unless staff believe that there is evidence of sufficient risk of harm to Mr K or to others that would justify intrusion into what is a private matter.

Conclusion

We expect privacy in our own homes and the right to behave in ways that others might disapprove of without interference. Healthcare professionals should provide such a level of privacy for patients who spend a long time or the end of their lives in hospital. For these patients privacy may be one of the few freedoms they can enjoy, and it is relevant to ask them how much privacy they would have in their own home. Good reasons are needed for accepting a lower level of privacy in hospital.

Commentary: Hospital can never be home

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The problem is that hospitals are not home, and never can be. The development of units for young disabled people in the 1960s and 70s raised hopes that homely environments could be created within the NHS. These aspirations were not realised; nor were they realistic. This has led to moves to create small family units in community settings and the provision of adequate facilities to maintain people in their own homes. Regrettably, facilities and resources remain limited and people are still admitted to hospital for respite care. Unless respite care involves assessment or treatment, hospitals of any sort are an inappropriate environment for most people with chronic neurological disease.

Underlying the question of the nature and use of hospitals is the wider issue of the purpose of the NHS. The NHS is probably not there to provide a “home,” however much we may want to transport home life into an NHS hospital.

Mr K’s habit might distress others

Cannabis is still illegal, although many people do smoke it. Whether it is a useful drug in multiple sclerosis is a matter for debate, but it is not prescribed officially. Although the ward staff may be sympathetic to Mr K’s predicament, they cannot allow him to smoke cannabis. Public servants are obliged to stay within the

law and making exceptions could lead them down the “slippery slope” of acquiescing to all sorts of illegal practices. Apart from this, the environment of many rehabilitation units would mean that Mr K’s smoking of cannabis would impinge on the privacy of others, who might find his habit distressing.

Eating cake, however, seems harmless enough. The staff are certainly not detectives and if Mr K eats cannabis cake they should have no means of finding out. The relationship between Mr K and staff should be one of mutual trust, however, which places an obligation on Mr K and his mother not to deceive the unit once the matter has been discussed and permission refused.

Sexual relationships are important to disabled people

Sexual relationships in hospital are a problem because of lack of privacy. There is no reason why sexual relations should be barred in hospitals, providing the privacy and feelings of others are protected. This can be a very important part of the life of someone with a chronic disability. The failure to provide facilities for sexual relationships may be a reflection of the attitudes and perceptions of able bodied staff to people with disabilities.

Commentary: Silence may be the best advocacy

Ruth Carlyle

Healthcare professionals and voluntary organisations supporting people with medical conditions act as advocates upholding the rights of their clients. In the case of Mr K, Savulescu et al suggest that the best advocacy can sometimes be to remain silent.

Cannabis and multiple sclerosis

The Multiple Sclerosis Society is often contacted by people who openly admit that they are breaking the law—people who are otherwise law abiding and would never have considered taking an illegal substance if they had not believed it might help them to cope with their symptoms, such as spasms, bladder control, or fatigue. Some people indicate that they have benefited from cannabis; some say that taking cannabis has had no impact on their lives with multiple sclerosis; and others report that it has made some of their symptoms, such as balance, worse. When we are contacted by people who volunteer the information that they are breaking the law, we respect their privacy as adults who have chosen to take cannabis for therapeutic benefit in their own homes.

Privacy in hospital ... and at home

Choices in life can be restricted severely by multiple sclerosis, and any additional curtailment of independ-

ence is therefore important. The greater the threat to privacy, the more it is prized. How far then should privacy extend? In a hospital, the ethical dilemma outlined by Savulescu et al is more complex. The authors suggest that the rule of thumb which we should be using is the degree of privacy that a person would experience in their own home. While Mr K was living with his mother, it is unlikely that any outsider would have noticed that Mr K was eating or smoking cannabis if he chose to hide the fact. Nevertheless, Mr K's privacy at home would be compromised by the closeness of his relationship with his mother and his need to be cared for by her. Privacy is not absolute at home or in hospital, but relationships operate at different levels according to context. Professional carers should not assume that they have the right to be as intimate as a family carer; the level of relationship should be more like that of a guest or colleague sharing a part of a person's life.

Caring for people has to involve concern for them as individuals with the right to make choices; it means not asking questions which breach their privacy. In this situation, ignorance may not be bliss, and it is certainly not an easy option, but it respects the privacy of the individual as a person rather than a patient.

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Commentary: Nurses should recognise patients' rights to autonomy

Pippa Gough

When people become dependent on others for care, their choices and actions may be affected and channelled by their carers' moral judgments and values about what is good and right. Although this extends across daily living, it is brought into sharp focus in relation to two key areas—the choice to break the law and the freedom to have sex as one wishes.

Although the case of Mr K highlights the former, in this instance the desire to use illegal drugs, the issues raised are equally applicable to the second area concerning sex and sexuality. Ultimately, we are discussing the principles underpinning the patient's right to autonomy and the nurse's obligation to maintain and promote this.

Patients' autonomy underpins professional practice

Nursing has struggled as much as any of the professions to shake off the practices of paternalism, the creation of dependency, and coercion, however subtly or benignly these are presented. We have probably been successful in raising the debate even if we have not influenced completely the way we deliver care.

The nurses' code of professional conduct, which provides the fundamental framework for professional practice, has strongly influenced these changes.¹ Recognition of a patient's autonomy underpins the code. At its most fundamental, this means respecting individuals' choices concerning their lives and, where necessary, providing an environment of privacy and confidentiality so that these choices can be pursued.

Personal privacy and public peril

The limitations to a nurse's duty of care in this respect are tempered only by the balance between the protection of personal privacy and the threat of public peril. In other words, this duty of care extends beyond the individual to society, and nurses are accountable for their actions in terms of each. The dividing line between the two, however, is rarely clear and dilemmas abound. Moreover, the nurse's own values may colour his or her interpretation of what might infringe the public interest, especially if this involves unlawful activity.

In the case of Mr K, the possible consumption of cannabis within the ward, which is after all his home during the respite period, does not seem to threaten

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the public interest in the slightest. Protection of Mr K's privacy therefore remains paramount. The nurses involved are not sure that cannabis is being consumed, and as this knowledge might affect their legal position, they should investigate no further unless this may present problems in respect of potentially harmful drug interactions. They should respect Mr K's right to

consume cannabis if he wishes, and to do so on the ward, without further questions being asked. Promotion of autonomous action in relation to pursuing sexual relationships should be dealt with similarly.

1 United Kingdom Central Council for Nursing, Midwifery and Health Visiting. *Code of professional conduct*. London: UKCC, 1992.

Commentary: Patients should have privacy as long as they do not harm themselves or others

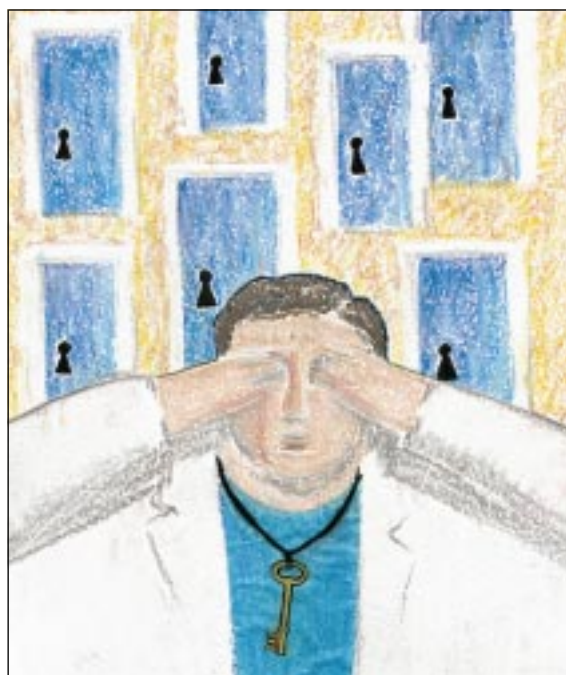
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Medical care requires the invasion of privacy. Patients must expose their innermost thoughts, their bodies, and their sickrooms to strangers. But to protect human dignity, health providers should limit invasions to those necessary to accomplish the goals of their patients.

Privacy of personal space

The case of Mr K centres on the privacy of personal space. The critical sentence in the case study of Savulescu et al begins "If hospital is home." The hospital is literally home if, as happens in many nursing homes in the United States, the patient is expected to live there until death. In these cases we should ensure that patients live their lives as they see fit, provided their actions do not seriously harm others. For example, sex with a consenting adult (with the door closed), reasonable amounts of alcohol, choices in food, ability to keep a locked drawer, freedom to take walks outside, guests of their own choice, telephone services, and the like remain important for many hospital patients. Yet the hospital is not usually home, and very few people would like it to be. Moreover, the contemporary trend is to transform homes into hospitals, rather than hospitals into homes.



Should ethical questions be treated as legal problems?

Mr K is in an intermediate position. He has a home, but is admitted periodically to hospital for respite care. Should he be deprived of the cannabis that his mother supplies him with at home? The reasoning in this case illustrates a pervasive and fundamental problem in modern medical ethics—the tendency to treat all ethical questions as legal problems.¹ Thus, the nursing staff and the case presenters rely almost exclusively in their analysis on their personal (I take it, non-legal) interpretation of English law. We are told, for example, that it is against the law if the staff “knowingly allow the consumption of illegal substances on hospital premises,” and that section 8 of the Misuse of Drugs Act 1971 forbids the “occupier of a premises knowingly to permit the consumption of illicit drugs.”

A pragmatic approach to privacy

Whether the law actually applies here requires an extensive legal analysis. While there is no explicit exception for medicinal use of “illicit substances,” I would be very surprised if a prosecution has ever been attempted of a doctor or nurse who made a reasonable judgment that use of cannabis in circumstances such as these should be allowed. (And the “premises” in section 8 probably apply to the venues of parties and other social gatherings, not hospitals.) As in all decisions concerning medical ethics, the focus should be on the patient and his or her wellbeing. If allowing his mother to supply cannabis in cake helps medically, does not harm any other patient or staff member, and is what Mr K wants, it should be permitted.^{2 3}

Finally, I would revise the three proposed limitations on patients' privacy by deleting the third altogether (resource allocation is really a separate issue) and combining the first and second. Thus, patients should be free to pursue their own interests and activities so long as this pursuit does not harm others or cause serious harm to themselves.

1 Annas GJ. *Standard of law: the law of American bioethics*. New York: Oxford University Press, 1993.

2 Kassirer JP. Federal foolishness and marijuana. *N Engl J Med* 1997;336:366-7.

3 Annas GJ. Reefer madness: the federal response to California's medical marijuana law. *N Engl J Med* 1997;337:435-9.

Urgency and priority for cardiac surgery: a clinical judgment analysis

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The Clinical Standards Advisory Group has expressed concern over the lack of clear criteria with which to accord priority to patients awaiting coronary artery bypass surgery.¹ Until recently, the most notable research on what determines "urgency" was to be found in reports from Ontario which point to variations between doctors and institutions in the criteria they use to place patients in a queue.²⁻⁴ Earlier this year the New Zealand National Advisory Committee on Health published its findings on the impact that some social factors, such as the threat to independence, the care of dependants, or the patient's ability to work, might have on decisions related to priority.⁵

The influence of demographic or lifestyle factors, such as age or smoking habit, on waiting list priority has been debated prominently in the United Kingdom.^{6,7} Doctors may take an individual view of the probable effectiveness of revascularisation in some patients (for example, smokers compared with non-smokers). However, neither the perceived efficacy of the procedure nor the distinction between "urgency" (the speed required to intervene to obtain a desired clinical outcome) and "priority" (the relative position on a surgical waiting list) has yet been investigated. Doctors might agree that a patient who smokes needs urgent intervention but disagree over the priority this patient should be accorded on a waiting list for surgery.

In response to the Clinical Standards Advisory Group report, a regional workshop sponsored by the Northern Ireland Clinical Resource Efficiency Support Team was convened in the spring of 1996 to address these issues. Two main research questions were:

- Do clinicians pay attention to demographic and lifestyle factors when making urgency and priority judgments?
- Do disagreements between clinicians arise out of differences in how they attend to clinical and demographic factors in arriving at these judgments?

Methods

The key task which participants ("judges") undertook before the workshop was an appraisal of "paper patients" (as in Ontario and New Zealand). In fact, the cases were based on a random sample of real patients who had undergone bypass surgery in Northern Ireland in 1991.⁸ Each patient was described by 10 clinical "cues." A sample case is shown in figure 1, while table 1 summarises the patients' characteristics. Each participating doctor was given a folder of details of 60 patients, of which 10 were duplicated cases, to assess.

Urgency

The exercise was carried out in two stages. Firstly, the doctor had to consider each case independently, and, using a visual analogue scale, indicate his or her views on the urgency of the case for surgery (fig 1). Doctors also indicated their views on the probable effectiveness

Summary points

Scoring systems developed to allocate priority for coronary bypass surgery may have potentially competing objectives, such as ensuring that the most urgent cases are treated first or that added life years gained or the quality adjusted life years are maximised in those waiting

The scoring systems so far devised have not made their specific objectives clear and have not distinguished between "urgency" and "priority"

Judgments about urgency and priority can produce different weighting for demographic and lifestyle factors such as age and smoking habit

Lifestyle characteristics often influence doctors' judgments on priority independently of their beliefs about the probable effectiveness of surgery

of coronary bypass surgery in improving symptoms, reducing the risk of infarction, and extending the patient's life.

Priority

When this work had been completed, the folder was returned to the authors. The cases, which had originally been in random order, were then reordered in the folder according to the urgency scores of the particular "judge" in question. At this stage, the 10 duplicate cases were removed. The judges were then asked to rearrange the cases, in any way they saw fit, to reach a final priority order for surgery (1-50).

Statistical methods

Multiple regression analysis was used to express the relation between judgments of urgency or priority for surgery and the demographic and clinical cues. Stepwise (backwards) elimination of variables was used to select these for the model. To minimise the risk of rejecting cues inappropriately, a relatively conservative P value of 0.10 was set.

The contribution of each cue to the model is represented by its contribution to r^2 , which was assessed by dropping each variable in turn from the model (the change in the type II sum of squares, cr^2). We also compared equations from different judges in terms of the cr^2 relative to that of all the other cues in the equation (rcr^2)—a method that standardises for variation in the models' explanatory power.⁹ Though neither method overcomes entirely the problem of collinearity, the rank order of importance of the cues in the decision models was not changed. (Data in table 2 relate to the first method.)

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Patient no 10

Please examine the patient's details given below and respond to the questions at the bottom of the page

AGE	39
SEX	MALE
SMOKING STATUS	NON-SMOKER
PERCENTAGE OF IDEAL WEIGHT	114%
EXPECTED PROCEDURE RELATED MORBIDITY/MORTALITY	AVERAGE
EXERCISE STRESS TEST	NOT HIGH RISK
CCS ANGINA GRADE	CCSI
LEFT VENTRICULAR FUNCTION	NORMAL
LEFT MAIN STEM STENOSIS %	0-49%
NUMBER OF DISEASED VESSELS (other than left main stem)	0

Indicate your views on the following questions by drawing a short vertical line somewhere on the horizontal lines below.

By having surgery, how much improvement in this patient's anginal symptoms would you expect?

None Symptoms eliminated

What difference will surgery make to the chances of non-fatal infarction?

No difference Eliminate risk

By having surgery, what GAIN in life expectancy is this patient likely to acquire?

Yrs Months

Indicate your views on the urgency of the case for surgery by drawing a short vertical line at some point on the horizontal line below

Routine waiting list entry For next available theatre list

What do you consider to be the maximum safe waiting time for this patient?

Maximum safe waiting time

"1" = <1wk; "2" = 2-4 wks; "3" = 5-12 wks; "4" = 3-6 months; "5" = 6-9 months; "6" = 9-12 months

Insert code number

Fig 1 Case appraisal form

The regression coefficients represent the strength of effect on the dependent variable. Categorical variables (with n categories) were fitted when appropriate, using n-1 dummy variables.

Results

Sixteen cardiologists, four general practitioners, four cardiac surgeons, and nine consultant physicians with an interest in cardiology participated. There was a high intraclass correlation between urgency scores for the 10 duplicate cases (mean:median, 0.79:0.88).¹⁰

Determinants of variability in responses

Before determining the urgency and priority policy models of each judge, we assessed which case characteristics were associated with greater or lesser dispersion in responses between doctors. More severe angina class and left main stem stenosis were associated with less dispersion in responses for urgency scores ($t=4.7$, $P=0.0001$; and $t=5.2$, $P=0.0001$ respectively). Smoking habit was the major determinant of the scatter of priority ranks, as greater variation was seen in priority ranks for smoking than non-smoking patients ($t=2.4$; $P=0.02$).

Initial decision models

Once it had been determined that some case characteristics affected the variability in responses between doctors, a decision model was derived for each of the 33 judges. Table 2 illustrates the results for three judges. As well as giving the regression coefficients (expressing the change in urgency score, or priority rank, for a unit change in the value of the cue), table 2 shows the relative contribution of each cue to the final decision model (calculated as described in the methods section). The models generally had high explanatory power—the mean r^2 was 73% for urgency judgments and 82% for priority judgments. (Details are available from us.)

Figure 2 shows the frequency of demographic and clinical clues in the doctors' decision models. Consensus is evident on the inclusion of major clinical variables such as angina class, left main stem vessels, and the extent of disease (the number of vessels affected). However, even with allowance for a 1 in 10 chance of a type I error (that is, including a variable with no explanatory power in reality), the urgency judgments of a few doctors were affected by the demographic cues of age, sex, smoking habit, and body mass index (weight(kg)/(height(m)²)). Figure 2 also shows that for some doctors the demographic variables affected priority judgments independently of their influence on perceived urgency.

Table 1 Characteristics of the "paper patients"

Clinical characteristic	No (%)*
Median (range) age (years)	57.5 (39 to 71)
Median (range) % of ideal weight	125.5 (103 to 158)
Sex:	
Male	39 (78)
Female	11 (22)
Smoking status:	
Non-smoker	36 (72)
Smoker	14 (28)
Expected morbidity/mortality related to procedure:	
Average	40 (80)
Higher than average	10 (20)
Exercise stress test:	
High risk	40 (80)
Not high risk	10 (20)
CCS angina grade:	
I	5 (10)
II	17 (34)
III	14 (28)
IVa	5 (10)
IVb	5 (10)
IVc	4 (8)
Left ventricular function:	
Normal	32 (64)
Abnormal	18 (36)
Left main stem stenosis:	
0-49%	43 (86)
50-74%	2 (4)
≥75%	5 (10)
Severely diseased vessels:	
0	4 (8)
1	10 (20)
2	15 (30)
3	18 (36)
4	3 (6)

*Except where stated otherwise. CCS=Canadian Cardiovascular Society.

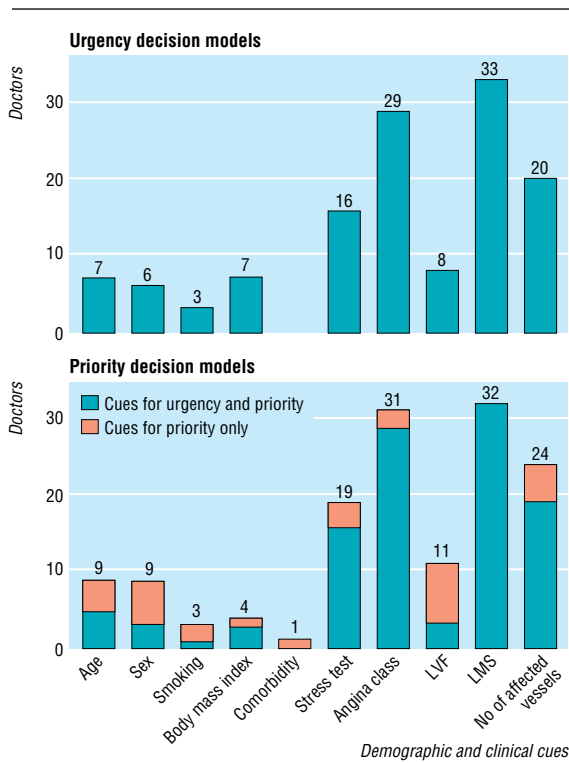


Fig 2 Frequency of demographic and clinical cues in decision models of urgency and priority. LVF=left ventricular function, LMS = left main stem stenosis

Models including perceptions of efficacy

Perceptions of urgency and priority may be influenced not only by the weighting given to particular clinical cues but also by the doctors’ perceptions of the probable efficacy of surgery in particular patients. We derived further policy models, after introducing into the equation the judge’s views about the capacity of the operation to relieve symptoms, to reduce the risk of infarction, and to prolong the patient’s life. The rationale behind this was that if a variable—for example,

smoking—were an arbiter of priority judgments, its effects might logically be mediated by its influence on the perceived capacity to benefit. A modest improvement in the fit of the models resulted. The mean r^2 for all doctors increased from 73% to 80% for judgments on urgency and from 82% to 86% for those on priority.

Although a few models were influenced by the demographic cues, the magnitude of this effect (reflected by the β or regression coefficient, which expresses the change in priority rating that accrues from each unit change in the clinical variables) was generally much smaller than that of the major clinical cues such as the severity of angina or left main stem stenosis (fig 3).¹¹

Discussion

What do we think scoring systems will achieve?

Our approach differs from that of the Ontario group. Firstly, by using data from real patients we hoped to avoid the potential for unrealistic combinations of clinical cues. Secondly, we derived decision policy models for each judge, whereas Naylor et al produced a composite regression model after averaging the ratings of their panellists.³ The validity of such an approach has been seriously questioned.¹¹ Thirdly, we addressed the influence of demographic and lifestyle factors and the judges’ beliefs about the probable efficacy of surgery.

We differed from the New Zealand group, too, in that we distinguished between urgency and priority, and we showed that this can affect the weight given to some factors.⁵ However, the wording in the New Zealand study is noteworthy: “Physicians were asked to consider what a reasonable waiting time would be for each patient, considering an adequately, not infinitely funded service... Reasonable waiting time was considered indicative of likely benefit and used as the outcome variable in our analyses.”⁵ Note the tautology in their approach. Weights (supposedly reflecting the capacity for surgery to affect life expectancy or quality of life) were first gleaned from

Table 2 “Urgency” and “priority” decision models of three sample judges

Judge		Age	Sex	Smoking	Body mass index	Expected morbidity related to procedure	Exercise stress test	CCS angina class	Left ventricular function	Left main stem stenosis	No of vessels affected	r^2
Urgency score												
1	Contribution to decision model (%)	—	—	3	—	—	3	28	—	6	3	0.80
	Unstandardised β coefficient (95% CI)	—	—	-11.5 (-21.2 to -1.72)	—	—	12.8 (0.63 to 25.1)	38.8 (24.7 to 53.1)	—	38.0 (5.0 to 71.0)	18.0 (1.7 to 34.3)	
2	Contribution to decision model (%)	—	—	—	—	—	—	15	—	3	—	0.92
	Unstandardised β coefficient (95% CI)	—	—	—	—	—	—	54.4 (42.1 to 66.7)	—	38.2 (18.2 to 58.2)	—	
3	Contribution to decision model (%)	—	—	—	—	3	—	76	—	12	—	0.78
	Unstandardised β coefficient (95% CI)	—	—	—	—	12.1 (-0.2 to 24.4)	—	74.5 (60.2 to 88.8)	—	38.1 (20.3 to 55.9)	—	
Priority ranks												
1	Contribution to decision model (%)	—	—	2	2	—	—	38	2	8	4	0.88
	Unstandardised β coefficient (95% CI)	—	—	4.2 (0.6 to 7.8)	0.1 (0.04 to 0.3)	—	—	-24.4 (-29.4 to -19.4)	-5.1 (-9.2 to -1.0)	-24.3 (-38.8 to -9.8)	-10.3 (-16.6 to -4.0)	
2	Contribution to decision model (%)	—	—	—	—	—	—	9	—	1	—	0.93
	Unstandardised β coefficient (95% CI)	—	—	—	—	—	—	-14.3 (-18.9 to -9.8)	—	-9.8 (-17.2 to -2.4)	—	
3	Contribution to decision model (%)	—	3	—	2	—	5	51	—	4	—	0.88
	Unstandardised β coefficient (95% CI)	—	6.0 (2.0 to 10.1)	—	-0.2 (-0.3 to -0.05)	—	-8.6 (-13.0 to -4.1)	-31.8 (-36.9 to -26.7)	—	-10.4 (-16.5 to -4.3)	—	

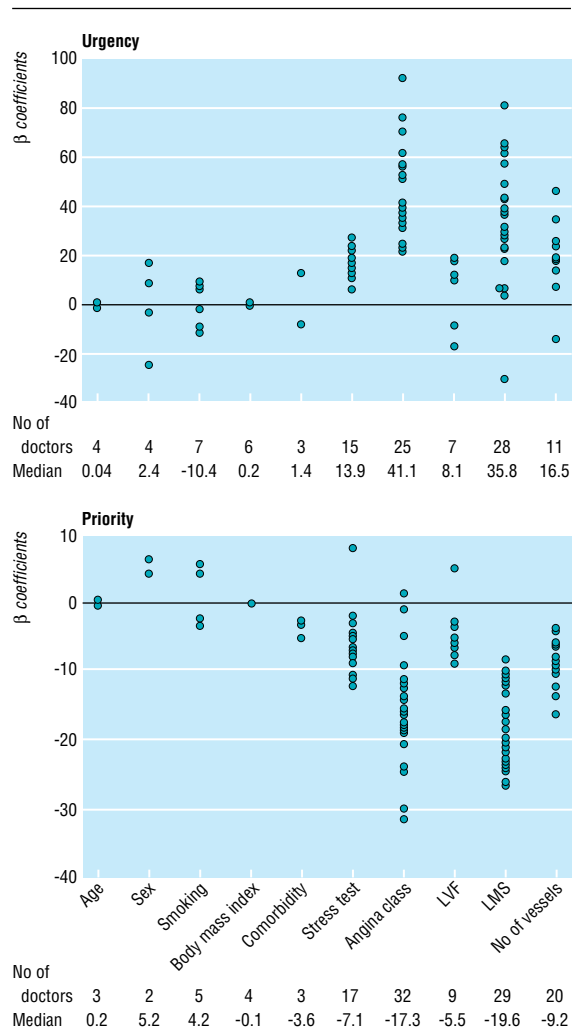


Fig 3 β Coefficients (unstandardised) for clinical cues in decision models of urgency and priority. Age=per decade, sex=men v women, smoking=smokers v non-smokers, body mass index=per additional 10% above ideal, stress test=high risk v not high risk, angina class=stable angina (grade IVb/c v Canadian Cardiovascular Society grade I/II, LVF=abnormal v normal left ventricular function, LMS=left main stem stenosis >75% v <50%, no of affected vessels= \geq 3 affected v 0 or 1

published reports and then “adjusted” after observing their correspondence with the regression weights, which were derived under an assumption of adequate funding. It can only be assumed that adequate funding implies that those with a material capacity to benefit would have surgery provided.

Somewhat perversely, a few of the weights, such as that applicable to age, were imposed on or adjusted externally to the scoring system. In addition, the dataset was pruned to exclude non-elective cases, so there was a preconceived notion of capacity to benefit that was not subject to investigation.⁵ Debate about what constitutes a non-elective case is bound to be vigorous—the urgency and magnitude of any benefits of surgery in patients with unstable angina are different, but they have been overestimated by many doctors.

What do we think surgery will achieve?

The apparent consensus over including clinical variables such as the angina class or extent of disease in the urgency and priority policy models in our study was not surprising. Meta-analyses have already shown

how these variables may affect the outcome of revascularisation.^{12 13} For groups devising urgency scoring systems based on these variables, however, a few caveats exist. Firstly, we cannot assume that cardiologists are always able to assess objectively the relation between the patient’s clinical history and the state of his or her coronary anatomy.¹⁴ Some may systematically overestimate the degree of luminal stenosis before treatment and underestimate the residual stenosis, which might give a biased view of treatment success.¹⁵

Secondly, clinicians seem to weight reduction in the risk of death more than improvement in symptoms.¹⁶ This would seem reasonable, if doctors did not tend to overestimate risk¹⁷ and to believe that most patients who die while waiting for revascularisation would have been saved by surgery.¹⁸ Even in our fairly expert group the average perceived gain in life expectancy from surgery for the 29 patients who had neither left main stem disease nor triple vessel disease was 2.5 years.¹⁹ Finally, although the state of the coronary anatomy and angina class were included in most final decision models, our preliminary analysis clearly indicated that these factors were important determinants of the variation in the judgments made by these doctors.

Are we driven by the evidence or by our values?

Demographic variables have been the focus of more contentious debate. While little evidence exists that the relative efficacy of surgery (that is, compared with continued medical treatment) is any different for smokers than for non-smokers,²⁰ or for fat patients than for lean ones,²¹ or, within bounds, for young than for old people, we surmised that a clinician who would give priority to one group or another would do so from such a belief.

Before perceptions of surgical efficacy were included in decision models for priority, the numbers of doctors influenced appreciably by demographic and lifestyle variables were: three for smoking habit, four for body mass index, and nine for age. When doctors’ perceptions of the effectiveness of revascularisation were included in the models, only one of the three doctors eliminated smoking habit and two of the four eliminated body mass index as important determinants. However, age was eliminated in all nine instances. The overall numbers of doctors for whom smoking habit, body mass index, or age were significant determinants (either with or without accounting for their views on efficacy) were six, seven, and 11 respectively. Our conclusion, for the lifestyle characteristics at least, is that when these variables were deemed important in decisions about priority for surgery, their influence was usually independent of effects they were perceived to have on surgical efficacy.

Consensus on allocating priority was difficult to achieve because original clinical trials were not designed to determine the risks of delay. Judgments about the appropriateness of care may nevertheless be affected by how the outcomes and the risks are perceived. Indeed, sometimes “we may enter a debate with an established prior belief, bias or prejudice ... and seek to maintain established medical or scientific paradigms by selecting evidence that supports those beliefs.”²² By sharing their decision models in discussion groups, our doctors made the impact of prior beliefs more evident. Only a few were influenced noticeably by demographic variables in their

decisions about urgency or priority. In fact, the size of the effect of these variables was far outweighed by the clinical cues. There are thus important lessons for those taking forward the recommendations of the Clinical Standards Advisory Group.

Firstly, health authorities who adopt the Ontario or New Zealand scoring systems must note that these do not take account of the distinction between urgency and priority—a distinction we find many clinicians seem to make. Secondly, the relative weight that doctors give to clinical and demographic or lifestyle factors is different for urgency and priority judgments. As Hughes and Griffiths point out: “The overlap between a technical discourse dealing with risk and a moral discourse dealing with character opens the way for unacknowledged shifts between the two. There is space for doctors to act according to their perceptions of deservingness, while accounting for their actions in terms of medical benefit.”²³

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Supermarket cigarettes: the brands that dare not speak their name

Martin J Jarvis

In terms of brand shares, the cigarette trade in the United Kingdom is dominated by the multinational tobacco companies, whose brands together hold over 90% of the market. But the situation in terms of numbers of brands is quite different. Recent years have seen a proliferation of brands sold by one retailer only (termed supermarket own label brands). In 1995, 153 (54%) brands monitored by the Laboratory of the Government Chemist were supermarket brands, compared with 114 (46%) from multinational tobacco companies and 17 (6%) brands of limited availability (for example, the brand sold in the House of Commons—“House of Commons King Size”). This contrasts with 10 years ago, when only 4% were supermarket brands.

Supermarket brands sell at a substantial discount and are not advertised, and there is little public awareness that major retailers are active players on their own account in the cigarette market. The market share held by supermarket brands could expand, particularly if cigarette advertising is banned and as the real cost of cigarettes increases. This article aims to document the situation, to draw up a profile of people who smoke these brands, and to comment briefly on some of the issues raised.

Summary points

All the main supermarkets sell own label brands of cigarettes; these make up the majority of brands on sale in the United Kingdom

Most supermarkets do not put their name on the packet, suggesting their awareness that involvement in the tobacco trade sits uneasily with the healthy image they like to promote

Supermarkets' own label brands currently have a market share of 7%, but this could increase if there were a ban on advertising cigarettes

Supermarket brands sell at a 20% discount and appeal to smokers who are poor, elderly, mainly female, and more heavily dependent

Supermarket brands exploit groups who can least afford to smoke, suffer most from smoking, and most need to give up

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Supermarket brands

Supermarket brands typically carry either no identification of their source or the name of one of a small number of independent tobacco companies. With rare exceptions, they do not carry a retailer's name in the way own label brands of other products usually do. But each brand is made for one retailer and sold only through its stores. Supermarket brands were therefore ascertained by inspecting the shelves in different stores, followed by telephone calls to confirm brand identity. Table 1 lists the main retailers and their brands. Each of the main supermarket chains sells these brands, as do cash and carry outlets and wine merchants. Apart from Asda, none of the main supermarkets has its own name on the packet. The average price for these brands (20 king size cigarettes) is about £2.48, 20% less than the brand leaders (£3.36 recommended retail price, but often selling for about £3.20). The total value of supermarket cigarette brands is estimated at £720 million per year out of a total tobacco market of £12 billion.¹

Who smokes supermarket brands?

Data from the general household survey for 1994² were used to estimate the market share of supermarket brands and to construct a profile of people who smoke these brands. The general household survey is a continuous national survey based on a representative sample of private households; every two years it includes questions on smoking. It is the principal national source of information on smoking habits. In the 1994 survey, information on the brand smoked was provided for 3928 (1691 men, 2237 women) of 3961 adult smokers of manufactured cigarettes. As no single supermarket brand commanded a substantial market share, smokers of these brands were grouped into a single category. The market share of supermarket brands overall was 7.2%. The sales weighted yields of these brands were 12.3 mg of tar, 0.9 mg nicotine, and 14 mg carbon monoxide—appreciably more than the 10.7 mg tar, 0.8 mg nicotine, and 12.2 mg carbon monoxide for other brands. Smokers of supermarket brands tended to be older, and there was a preponderance of women (table 2). People who smoked supermarket brands were compared with other smokers by means of logistic regression analysis (table 3). They were poorer, as shown by their increased likelihood of having a manual

Table 1 Own label cigarette brands of some major retailers

Retailer	Brand
Asda	Balmoral
Booker	Gold Mark; First; Red Band; Silver Strand; Double Gold
Co-op	Kingsmen; Windsor Blue
Somerfield	Solo
Kwik-Save	18's; Conway; Buckingham; Madison
Londis	Londis
Morrisons	Metro
Safeway	Virginia Star
Sainsbury	Statesman
Spar	Sky
Tesco	benington
Thresher	Lambeth
Victoria Wine	Beaumont
Waitrose	Oscar

Table 2 Percentage (number) of cigarette smokers smoking supermarket brands. Numbers are total respondents to general household survey, 1994²

Age (years)	Men	Women
16-24	2.3 (7/299)	2.6 (9/348)
25-34	3.5 (13/373)	5.2 (27/523)
35-49	4.4 (23/526)	8.0 (52/650)
50-59	7.6 (18/237)	7.8 (23/296)
≥60	15.6 (40/256)	16.3 (68/420)
All ages	6.0 (101/1691)	8.0 (179/2237)

Table 3 Odds of smoking supermarket brands of cigarettes relative to mainstream brands brands.* Variables are adjusted for each of the other variables in the model

Characteristic	Odds risk (95% CI)	P value
Age	1.04 (1.03 to 1.05)	<0.0001
Female sex	1.45 (1.12 to 1.89)	0.01
Manual class	1.76 (1.32 to 2.35)	0.0001
Rented housing	1.37 (1.06 to 1.77)	0.02
Time to first cigarette†	0.91 (0.83 to 0.99)	0.02
Cigarette consumption‡	1.31 (0.97 to 1.78)	0.08

*Data from general household survey 1994.²

†Six level trend variable, ranging from <5 minutes to >2 hours after waking.

‡Dichotomised as <15 cigarettes per day versus ≥15.

occupation and living in rented accommodation. They were also heavier smokers, whether judged by consumption of cigarettes or the time from waking to smoking the first cigarette of the day. These characteristics were similar in men and women.

Comment

There has been a rapid growth in own label cigarette brands in the United Kingdom. They are now sold by all the major supermarket chains. None of these brands individually commands a substantial market share. The general public seems unaware of their existence. Why should they be considered worthy of comment?

■ *“Food chains’ involvement in the tobacco trade sits uneasily with their image as purveyors of fresh, healthy food”*

The main food chains have promoted their image as purveyors of fresh, healthy food. Their involvement in the tobacco trade sits uneasily with this. The selling of cigarettes on the grounds that it is necessary to meet customers' needs may be a specious justification but is perhaps acceptable to many as a recognition of the realities of the market place. But own label brands go well beyond this passive servicing of customer demand. Supermarkets which arrange for the manufacture of own label cigarettes and sell them at a substantial discount are themselves active participants in the tobacco industry. No doubt identification with the tobacco industry is something they would wish to avoid. Recent comment indicates that concern about possible liability in tobacco litigation is leading a number of retailers to reassign ownership of their cigarette brand names to the tobacco companies that manufacture them.¹ There is a strong suggestion from this that retailers wish to profit to the maximum from their tobacco trade while avoiding both liability for harm to

their consumers' health and any explicit association of their names with the trade. This may explain why they do not put their names on the packets. Even the staff of the supermarkets that sell these brands seem unaware of their companies' involvement. These are the brands that dare not speak their name.

■ *“Retailers wish to profit to the maximum from their tobacco trade while avoiding ... any explicit association of their names with the trade”*

The attraction of own label brands to consumers is simple. By undercutting mainstream brands by up to 20%, they mitigate the effects of the annual increase in the real cost of cigarettes that is currently government policy. The responsiveness of own label sales to price increases is recognised by industry commentators.³ As the cost of tobacco continues to increase, and if mainstream brands lose their advantage from heavy advertising and promotion, these brands could take an increasingly large share of the market. In so doing, they

would work against the achievement of targets for reducing the prevalence of smoking.

As would be expected from their price, own label cigarettes appeal especially to the poor, to the elderly, and to more heavily dependent smokers. Own label brands in the United States appeal to just the same constituency.⁴ These are groups who are at high risk of smoking related diseases and who have a particular need to give up smoking, but for whom the availability of low cost cigarettes acts as a disincentive to giving up. Thus, even within the context of the cigarette market, own label cigarettes are not neutral. They exploit groups who smoke most, can least afford to smoke, suffer most from smoking, and most need to give up.

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Coping with loss

Bereavement in childhood

Dora Black

Infants do not come into the world as “empty slates” but bring with them complex behavioural systems. One system that has been well studied protects the child from danger during the long period of extra-uterine immaturity. It involves the development of mutual attachment behaviour (box), which ensures that the child does not stray far from a caretaker. Infants are active partners in the development of this behaviour, using instinctive behaviours to engage caretakers in protecting them. These include smiling, vocalising, crying, and, later, returning frequently to the secure base of the adult after exploratory forays.¹ Infant attachment is at its height at about 3 years of age and then becomes increasingly diffused by the development of other relationships, but it remains important throughout life, with later relationships qualitatively echoing the earlier ones.

For optimal emotional, social, and psychosexual development to occur, children need a warm, secure, affectionate, individualised, and continuous experience of care from a few caretakers who interact with them in a sensitive way and who can live in harmony with each other.

Separation and loss in childhood

Infants and toddlers react to separation from an attachment figure by protesting vigorously. If their cries are not successful in restoring the adult, protest eventually gives way to despair, and eventually, if they are not restored to their attachment figure, pathological states

Summary points

The pattern of attachment between infant and parent is rooted in instinct but modified by experience. It is an important source of security throughout life

Separation from a parent in early childhood is followed, in succession, by protest, despair, and detachment; feeding difficulties, bedwetting, constipation, and sleeping difficulties may arise

In later childhood the loss of a parent commonly gives rise to emotional and behaviour problems

Children bereaved in childhood may be vulnerable to psychiatric disorder later in life

Forewarning can help children to prepare for bereavement, and they usually benefit from viewing a dead parent and attending funerals and other rituals

Family support meetings can reduce morbidity after bereavement

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

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of detachment and indifference may ensue. They probably have little concept of death, and the disappearance of a parent, whatever the cause, will evoke similar reac-

tions. Thus a parent away for a few hours and one absent for longer both evoke the same separation anxiety in infants and toddlers older than a few weeks or months.² Even very young children can mourn for a lost parent, although the form of their grief differs from that of adults and older children.^{2, 3} Their reactions tend to be bodily ones such as feeding difficulties, bed-wetting, constipation, and sleeping difficulties.

By 5 years of age, most children can understand the difference between a temporary separation and death. They know that death is irreversible and universal, has a cause, and involves permanent separation and that dead people differ from live people in several respects: they are immobile, unfeeling, and cannot hear, see, smell, or speak. It is more difficult for children to understand that dead people change in their appearance, and this concept does not develop until nearer puberty.⁴

Children from 5 to 11 years are more likely to understand the physical changes that death brings and are helped by seeing these changes for themselves. They should be told what to expect, and they should be allowed to view the body if they wish. Exceptions may arise if the body is severely mutilated or if the child or parents have a strong aversion to the idea of viewing. In such cases additional support may be needed.

Children's characteristic response to the death of a parent is an increase in activity, and behavioural problems may result. Hallucinations of the dead person are a common feature of grief in adult life.⁵ They can also be experienced by young children, who may interpret them as evidence of the parent's return, or as evidence of persecution by the ghost of the dead parent because of imagined shortcomings on the part of the child, in which case they can give rise to severe anxiety. Because of their need for parenting, children who lose one parent often become anxious about the survival of the other, and they may protect that parent from knowing of their distress. That, and the difficulty of sustaining mood states in childhood, may lead the parent or teacher to believe the child has recovered from, or has not been affected by, a bereavement.



Components of attachment behaviour in infants

Behaviour that maintains attachment:

- Smiling
- Vocalising (babbling)
- Clinging
- Following

Behaviour on separation:

- Crying (protest)
- Restless searching
- High anxiety
- Irritability

Reactions to bereavement in childhood

The florid reactions tend not to last beyond a few weeks, with most children regaining their previous level of psychosocial functioning.⁶ However, as assessed by parental reports, children have higher levels of emotional disturbance and symptoms than non-bereaved children for up to two years, and up to 40% of bereaved children show disturbance one year after bereavement.^{7, 8} In direct assessments of bereaved children, Weller and colleagues found that 37% of their sample of 38 bereaved prepubertal children had a major depressive disorder one year after bereavement.⁹

Longing for reunion is common and may lead to suicidal thoughts in bereaved children and adolescents, although they are rarely acted upon.⁹ Other difficulties include learning problems and failure to maintain school progress.¹⁰

Long term effects of bereavement on children

Children who are bereaved early are more likely to develop psychiatric disorders in later childhood.¹¹ Rutter found a fivefold increase in childhood psychiatric disorder in bereaved children compared with the general population.¹²

Adults bereaved of a parent in childhood seem to be more vulnerable than the general population to psychiatric disorder, particularly depression and anxiety, and this is often precipitated by further losses.^{13, 14} Attempted suicide is more common in adults bereaved in childhood.¹⁵

Children who lose their mother suffer a reduction in the quantity as well as quality of care, and this may account for the finding of differential effect according to the sex of the deceased parent.⁹

Effects of the death of a sibling

Children compete for parental attention and often feel resentful of the attention given to a sick sibling. This can be heightened if a parent has spent time in hospital with the sibling. Guilt may be the predominant emotion that follows triumph at having survived when a sibling dies. Young children may believe that their hostile or ambivalent feelings actually caused their sibling's death, and this may lead to profound behavioural changes. If the sibling was older, and carried out some parental functions, the reaction may be similar to that after loss of a parent.



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Asked to draw her mother as she imagined she might be after radiotherapy for carcinoma of the breast, 6 year old Eva at first drew mother with a scarf to hide her bald head and then attempted to hide the scarf in a similar coloured background (purple). Subsequently she filled in the background with black and drew the "tombstone" below. Although she had not been told directly that mother was dying, she showed her therapist that she was aware of the likely future for her mother

Helping bereaved children

Children are rarely prepared for the death of a parent or a sibling, and yet we know from studies of bereaved adults that mourning is aided by a foreknowledge of the imminence and inevitability of death.¹⁶ Children who are forewarned have lower levels of anxiety than those who are not, even within the same family.¹⁷

When death occurs, young children in particular may need the concrete experience of seeing the parent after death. Bereaved adults find it particularly difficult to help a child in this way, and the general practitioner could offer to accompany the child. Similarly, children benefit from attending the funeral but need some protection from the raw expressed grief that may be shown at that time. Attending in the company of someone less affected by the death than the immediate relatives is desirable. This could be the child's teacher or someone from the family practice with whom he is familiar.

The monitoring and help with practical matters (applying for a home help, mobilising family support, ensuring adequate income, etc) needs to be accompanied by specific bereavement counselling for both the child and the surviving parent. A controlled trial of family therapy with children bereaved of a parent showed that the postbereavement morbidity of 40% at one year could be reduced to 20% by six sessions of family meetings which focused on promoting shared

mourning within the family and encouraging communication about the dead parent.^{8,9} Preventive counselling is properly the responsibility of the primary care team, utilising the resources of bereavement counselling services as necessary. Cruse (the national charity for bereavement care) publishes useful literature for bereaved children and their carers and provides training and bereavement counselling services. Dyregrov's excellent handbook for adults deserves a place in a practice library,¹⁸ and workbooks for children of primary school age can aid those counselling them.^{19,20}

Finally, the practitioner needs to be aware of the small number of children who may need more specialised help in recovering from depressive or other symptoms that may be associated with bereavement. These will include children who may have been partly instrumental in causing death (of a sibling perhaps), those who have gone through sudden and particularly traumatic bereavements, children who have suffered more than one bereavement, adolescents who express suicidal ideas, and children who do not respond to the initial preventive interventions.

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The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray Parkes and Andrew Markus, which will be published in May.

Correction

Mother knows best

This article by Kacker (10 January, p 144) contained misleading genetic information. Lipoid proteinosis is an autosomal, not a sex linked, recessive disorder. The fact that the child's parents were first cousins suggested the possibility of an autosomal recessive disorder, but would have been irrelevant in the case of a sex-linked one. The involvement of the two brothers, but not of the two sisters, must have been a chance occurrence.