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## Getting consent for necropsies

#### Perhaps we should seek consent to show necropsies to students

EDITOR-Sayers and Mair highlight the reasons for which hospital (consent) necropsies are performed and for which clinicians are now faced with the task of seeking informed consent-to confirm the cause of death, to answer diagnostic queries, and to obtain and retain material for research and teaching.1 Another key use of a necropsy, not mentioned on the consent form, is in undergraduate teaching. Many medical students will encounter the necropsy during their training, either witnessing the whole procedure or as a demonstration of the pathological findings of the procedure in which organs and tissues are displayed (perhaps with the patient's body in the background) before their return to the body.

Should explicit informed consent be obtained to use necropsy in this way? The short report by Westberg et al in the same issue serves to highlight the importance of obtaining consent for students to witness invasive procedures such as a vaginal examination, even though most patients do not object.2 Necropsy is no less invasive. Whether patients and relatives would object to a group of students viewing the body after death is not known. It is established, however, that "an important precondition for good education of medical students is that patients are prepared to participate in training."3 Failure to obtain consent denies the autonomy of both the patient and the

Some people argue that, once death has occurred and the decision to allow a necropsy has been taken, the worst is over and therefore the presence of students at the necropsy is of no consequence and does not require consent. This denies relatives the opportunity to be altruistic and know of the benefits that come to students from the procedure. We should be as concerned that consent is adequate as we are with who

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#### Most relatives give consent once reasons for necropsy are explained

Editor—As pathologists performing a large number of perinatal autopsies, we read Sayers and Mair's personal view with a mixture of sadness and disbelief.1 We do not want to increase the relatives' and (in our case) parents' grief with detailed descriptions of postmortem procedures. But current levels of information available mean that most already know the basics, and people want to have a choice. Most of the detailed explanations of what might happen to tissues and organs at a postmortem examination have been added to the consent form at the insistence of parents' pressure groups.

Teaching is essential for new doctors, all of whom need to learn at least the basics of pathology if they are going to be capable clinicians. Most of the research projects requiring postmortem tissues are clinicopathological studies. Almost all of them use tissues that will be retained for histological diagnosis anyway. Because we now need consent to retain even tissues used for diagnosis, clinicians could explain that this retention might help relatives in the future (including in future pregnancies and similar diseases in another member of the family).

Most pathologists retain full organs for teaching and training or research only at the specific request of a clinician. We are surprised that some doctors are prepared to give parents and relatives the consent form and let them deal with it by themselves in such a traumatic period.

Until recently there has not been much training in communications skills in medical schools, but surely opting out of the patientdoctor relationship at this time is not an answer. The main reasons for a hospital necropsy are to explain to the relatives what happened to the patient and to help the clinicians understand the disease process. It is not the pathologist who primarily benefits from a necropsy.

In our experience, most parents (and most hospital postmortem examinations are performed in perinatal cases) agree to the requests in the consent form for a postmortem examination once the reasons are explained to them, especially by a doctor they have met and trust. We are surprised that Sayers and Mair find it acceptable for a person whom the parents or relatives have never met before to come and talk to them at this time or at the time of the necropsy.

If clinicians want to discuss any aspect of the necropsy, including the reasons for requests other than diagnosis, we are all happy to help.

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1 Sayers GM, Mair J. Getting consent for autopsies: who should ask what, and why? *BMJ* 2001;323:521. (1 September.)

#### Bereavement teams might ask for consent for necropsy

EDITOR—As we work in histopathology we have a keen interest in the process of hospital necropsy and getting consent for necropsies.1 We can assure all clinicians that pathologists across the United Kingdom are acutely aware of the Alder Hey scandal, and caution abounds within the profession.

Custom does indeed dictate that clinicians involved in patient care approach relatives to seek consent for necropsy, but, although the new consent forms may be overly detailed, the amount of information one is required to give relatives in order to obtain genuinely informed consent has not changed. The total time needed to achieve consent has not altered greatly, although a small amount of time is required to take the relatives through the layout of what can be a slightly confusing form.

The process of asking relatives whether they want some parts of the body or some specific organs left intact is unhelpful to them and also to the pathologist. Indeed, incomplete necropsies, without the option to take samples for microscopic examination or toxicology tests, often fail to give the definitive answers desired; the utility of doing only a partial necropsy should often be questioned. It is also unrealistic, when one considers the logistics involved, to suggest that pathologists should consult families (in the middle of the procedure) when something interesting is found that may require the results of histological tests to diagnose fully.

As Sayers and Mair state, doctors are expected to be sensitive, but therefore why do they propose that a pathologist-not previously known to the patient or family and therefore less able to empathise with their situation-should approach relatives for consent?1 Staffing issues should also be considered. Clinicians are stretched for time, but moving the onus to pathology, which currently has the biggest consultant staffing crisis of any specialty, would only make matters worse.

Given the changes in the medicolegal climate, new, detailed consent forms are a necessity. Maybe the best way forward is to consider employing specially trained bereavement teams to deal with this process.

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## Genetics mediate relation of birth weight to childhood IQ

EDITOR-Matte et al reported an association between birth weight and childhood IQ.1 To control for confounding by maternal and family factors they examined this relation in sibships of the same sex and found an association between birth weight and IQ

Full IQ score at ages 5, 7, 10, and 12 of cotwins with lowest and highest birth weights in dizygotic and monozygotic twin pairs. Values are means (SD)

	Dizygotic twin pairs				Monozygotic twin pairs			
	No	Cotwin with lowest birth weight	Cotwin with highest birth weight	P*	No	Cotwin with lowest birth weight	Cotwin with highest birth weight	P*
All twins								
Birth weight (g)		2451 (436)	2804 (380)	0		2337 (427)	2545 (404)	0
Full IQ score:								
Age 5	77	99.4 (12.9)	102.6 (12.8)	0	81	102.9 (12.8)	105.3 (13.4)	0.01
Age 7	72	99.0 (13.9)	103.2 (14.5)	0	73	104.0 (15.1)	103.7 (14.0)	0.83
Age 10	75	104.1 (13.9)	106.8 (13.9)	0	75	108.0 (16.2)	107.6 (16.5)	0.70
Age 12	73	98.6 (12.8)	100.3 (14.1)	0.22	75	100.2 (13.9)	101.27 (12.5)	0.20
Gestational age >36	weeks							
Birth weight (g)		2550 (436)	2935 (333)	0	0	2535 (383)	2745 (353)	0
Full IQ score:								
Age 5	59	99.5 (12.7)	103.0 (11.9)	0	45	101.6 (11.7)	104.7 (13.3)	0.02
Age 7	56	98.2 (14.5)	104.0 (14.7)	0	42	101.1 (14.3)	101.3 (14.1)	0.90
Age 10	58	104.6 (13.7)	108.3 (12.2)	0	42	106.7 (15.1)	105.4 (16.1)	0.34
Age 12	56	98.7 (13.2)	101.73 (13.2)	0	41	97.4 (12.4)	98.3 (11.6)	0.39

<sup>\*</sup>IQ differences between cotwins with lowest and highest birth weights were tested with paired t tests.

within male sibships. This association may be mediated by genetic factors.

The impact of genetic factors on this association can be determined through the investigation of birth weight and IQ in twin pairs. Differences within dizygotic twin pairs are a function of both genetic and non-genetic factors, whereas differences within monozygotic twin pairs are almost completely caused by non-genetic factors. If genetic factors mediate the association between birth weight and IQ it is expected that for dizygotic twin pairs the association between intrapair differences in birth weight and IQ is positive, while for monozygotic twin pairs no association is expected.

In a Dutch longitudinal twin study the association between birth weight and IQ was measured in 170 twin pairs of the same sex.<sup>3</sup> Birth weight was obtained with a questionnaire, administered to the mother after the birth of the twins. Full IQ was obtained at ages 5, 7, and 10 with the revised Amsterdam child intelligence test (RAKTI), a Dutch intelligence battery, and at age 12 with the Wechsler intelligence scale for children.

Comparison between cotwins with lowest and highest birth weights showed that the dizygotic twins with the lowest birth weight had a lower IQ than their cotwin with the highest birth weight at ages 5 to 10 (table). This difference was not seen in the monozygotic twin pairs. Mean IQ was the same for the twins with the lowest and highest birth weights. When twin pairs with a gestational age of <37 weeks were excluded the results were similar. We also determined the association of intrapair differences in birth weight and IQ. At ages 7 and 10 this association was positive in dizygotic twin pairs (r=0.29, P=0.01; r=0.27, P=0.02)but not in monozygotic twin pairs (r = -0.02, P = 0.88; r = 0.01, P = 0.91)

Our results suggest that genetic factors mediate part of the association between birth weight and childhood IQ, at least until age 10. We found an association between intrapair differences in birth weight and IQ in dizygotic twin pairs. As twin pairs share influences such as prenatal factors, socio-

economic status, parental smoking, and parental age, the influence of these confounders is negligible. In addition, in monozygotic twin pairs, in whom intrapair differences reflect only environmental influences, the association between intrapair differences in birth weight and IQ is absent.

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# Quality of care for people with dementia

### Change in attitude is needed

EDITOR—Are readers surprised by Ballard et al's findings that nursing homes are failing the needs of patients with dementia? Probably not, especially if they spend any time in nursing homes either as a healthcare professional or as a relative or friend.

Ballard et al's conclusion that strategies to improve joint working between the agencies to provide integrated specialist services sounds good, but surely it's the day to day care that's failing people with dementia. Of course they need specialised services, but they need compassion, an understanding of their needs, appropriate activities, and human interaction. These things need time and a special kind of staff who enjoy working with elderly people with challenging problems.

Until relatively recently we were also failing children with severe learning dis-

abilities. Now we understand these children's needs and rights to education, choice, and social interaction. People who work with these children are highly regarded in our society, if not well financially remunerated. It seems to me that until we start to apply the same ethos of care to our elderly people that we apply to our ill and disabled children we will continue to fail them. We must always remember that one day it may be us sitting in that chair with no way of communicating our distress.

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## Dementia care mapping is inadequate tool for research

EDITOR—Ballard et al draw conclusions from observing residents' activities in establishments providing care for people with dementia that few specialist professionals would disagree with: that standards are poor and must be raised.¹ Their methodology, however, is potentially misleading if service providers use the dementia care index alone as an indicator of improved quality of care.

Dementia care mapping measures the subjective experience of the service user across three dimensions (type of activity, degree of comfort, and time). Standardisation of data is achieved through thorough accredited training, and the dementia care index is derived from aggregation of observations. Typically in our experience, the activity is observed during the working hours of people other than nurses and rarely during early mornings, evenings, and nights.

The paper refers to a standardised six hours of mapping in each home in the study but fails to extrapolate general and relevant data on the quality of the services provided across a 168 hour week. When longitudinal studies have used the dementia care index as