RESEARCH ETHICS

Recruiting donors for autopsy based cancer research

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A nurse counsellor attached to the ocular oncology service was employed as the research nurse. Following treatment of the tumour, patients attending for yearly review (2–3 years after treatment) were approached. The nurse ensured the patients met the inclusion criteria and assessed their current emotional wellbeing and support. To limit undue stress and anxiety, only patients who had accepted their diagnosis and treatment well and who were coping with their cancer were approached. Patients were reminded of the rarity of the condition and therefore of their importance to the researchers. The nurse then went through the information pack and answered any questions raised by the patient. The consent form requires signatures from both patient and next of kin who if present were included in all discussions. Following consent a donor card and a copy of the consent form were sent to the participants. Patients who had been discharged in the last five years or who were not due in clinic for some months were approached by mail. The nurse followed this up with a telephone call and an invitation to attend clinic to discuss participation.

In the first 10 months of the study 121 patients were approached. Of those who responded 87 agreed to take part and only 10 declined, a take up rate of 88.5%. Some of those approached by mail had either died already (n = 3) or had moved (n = 3). Some of the common questions raised during interview and the reasons for declining to take part are shown in box 1. One misconception that often arose was the difference between tissue and organ donation as patients often thought they were required to give the whole organ.

One concern about writing to patients was that it might cause unnecessary anxiety, however out of 78 letters only three individuals expressed any anxiety. One of these individuals was an elderly lady, living alone, who was very upset on receiving the letter. One suggestion to avoid this in future is to contact the patient’s GP before any approach is made to the patient. Nevertheless, because of the potential distress to patients by this approach we have now stopped this recruitment procedure.

DISCUSSION

Recruiting sufficient numbers of donors is a problem facing both clinical studies and organ transplantation. This can be even more of a challenge when patients have rare diseases such as uveal melanoma, where a high take up rate and multicentre—or even international—participation may be required. NICE recently reported that typically only 40% of those approached agree to take part in clinical trials and that improved communication is the key.7 The take up rate in this study of 88.5% is therefore very encouraging.

The use of expert staff who are experienced in dealing with the issues raised by discussions of death and dying are undoubtedly hugely important. In a recent study, the use of such staff combined with improved information led to a marked increase in the number of organ donors recruited.4 Comparison of the effectiveness of nurses and surgeons in recruiting patients has shown nurses to be equally as
Box 1

Questions raised during initial interview
- Have I already got liver disease?
- What are the symptoms of liver disease?
- What happens if I do get symptoms?

Reasons for declining to join the study
- Phobia about removal of body parts (20%)
- Don’t want to think about death (30%)
- Next of kin declined (30%)
- Thinks the body shouldn’t be disturbed (20%)

effective and more cost effective than surgeons, highlighting the important role of nurses in patient recruitment.  
The high take up rate in this study shows that if patients are approached in a sensitive manner and are fully informed, then the majority are happy to donate tissue to further research into their condition. We believe that a personal approach by the nurse counselar was a key factor in the successful recruitment of patients in this study. In addition, the inclusion of the next of kin at all points in the recruitment process is important as they need to be fully informed and aware of the participants’ wishes.

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REFERENCES