

Post-mortem collection of human joint tissues for research

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Objective. A feasibility study aiming to obtain post-mortem knee joint tissues from 10 donors for research.

Methods. Next of kin were approached by bereavement officers then informed about the project by the study nurse. Written consent was sought to collect bone, cartilage and soft tissue from both knees, and to extract data from medical notes.

Results. During the 4-month study period 259 families attended the King's Mill Hospital Bereavement Centre, 36 of whom met with the study nurse, 10 of whom consented to joint tissue collecting. The process of seeking consent required approximately 1 h of direct contact. Participants often looked to this as an extension of the bereavement counselling process and many expressed gratitude that some good might be derived from the death. Reasons for non-recruitment included operational restraints and relatives' distress. Donors were more likely to be male (90%) than were non-donors (49%, $Z = -2.6$, $P < 0.01$). Coroner's post-mortem examinations took place on similar proportions of donors (20%) and non-donors (19%, $Z = -0.06$, $P = 0.96$).

Conclusions. Post-mortem joint tissue collection for research remains feasible in the presence of a skilled, well co-ordinated, multidisciplinary team, even when post-mortem examination would not otherwise be required.

KEY WORDS: Post-mortem, Tissue, Ethics, Arthritis, Consent.

Human tissues continue to facilitate biomedical research. Ethics of collecting tissue samples post-mortem have been the subject of recent debate and guidelines [1–4]. In particular, the Royal Liverpool Children's Inquiry in the UK drew attention to the considerable distress caused to relatives who were unaware of, and had not consented to, the retention for research of organs from children undergoing post-mortem examination [1]. A subsequent census undertaken by the Department of Health confirmed that the practice of retaining organs and tissues at post-mortem examination had been widespread in the UK, and highlighted that such practice is now out of step with public expectations [5]. Emphasis on informed consent reflects the current view that tissues are 'donated' rather than 'abandoned'. Difficulties associated with seeking consent from recently bereaved next of kin have caused concern that research may be inhibited [6].

Consent for research on tissues samples collected after death may be independent of consent for post-mortem examination. Joint tissues are not normally collected during post-mortem examination, and also may be removed for research when more extensive examination is not requested. We undertook a feasibility study aiming to obtain post-mortem knee joint tissues from 10 donors for research.

Methods

Next of kin were initially approached about the study during their routine consultation with a bereavement officer at King's Mill Hospital. Interested next of kin met the study nurse (D. Wilson) as an extension of that appointment. She explained the nature of the request through face to face discussion, written information and consent form. Permission was sought to collect bone, cartilage and soft tissue from both knees, and to extract data from medical notes. The study nurse explained

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how tissues and data would be used for research, how they would be stored and for how long, and the extent of the next of kin's rights. Documentation of consent was retained by the next of kin and researcher, and by the mortuary to ensure appropriate identification of donors. Where appropriate, permission for tissue sample collecting was sought from the coroner. The end point for the study was on recruitment of the tenth donor.

Data are presented as median (range) or (interquartile range, IQR). Subgroups were compared by the Mann-Whitney test using Statistical Package for Social Science (SPSS, version 8, Chicago, USA). This study was approved by the North Nottinghamshire Local Research Ethics Committee and Sherwood Hospitals NHS Trust.

Results

During the 4-month study period 259 families attended the King's Mill Hospital Bereavement Centre, 36 of whom met with the study nurse, 10 of whom consented to joint tissue sample collecting. Nine donors were male, median age 80 yr, range 68–93 yr. Nine donors had died in hospital. Post-mortem examination was required on two of the three cases discussed with the coroner. A hospital post-mortem examination was not requested for any case. The minimum time from death to tissue sample collecting was 10 h.

The process of seeking consent required approximately 1 h of direct contact with relatives and close friends of the deceased. Participants often looked to this as an extension of the bereavement counselling process and many expressed gratitude that some good might be derived from the death. Reasons for non-recruitment of the 223 families who did not meet with the study nurse included operational restraints (e.g. high workload did not always allow sufficient time for introduction of the study by bereavement officers), and appraisal by bereavement officers that relatives were too distressed to consider the research adequately. In either case relatives were not invited to participate in the study.

Donors were of similar age (median 80, IQR 74–90) to non-donors (median 76, IQR 66–83, $Z = -1.9$, $P = 0.06$), and were more likely to be male (90%) than were non-donors (49%, $Z = -2.6$, $P < 0.01$). Non-donors whose families met with the study nurse were also more likely to be male (73%) than were those whose families did not meet the study nurse (46%, $Z = -2.6$, $P < 0.01$). Coroner's post-mortem examinations took place on similar proportions of donors (20%) and non-donors (19%, $Z = -0.06$, $P = 0.96$).

Discussion

Human tissues samples collected post-mortem contribute importantly to medical research, facilitating the understanding of disease mechanisms and contributing to drug development. However, individuals may have legitimate ethical, religious, emotional or other objections to the sample collection or use of tissues in research. Failure to involve bereaved families fully in

decisions about retaining tissues for research has led to considerable distress and recent adverse publicity [1, 4]. Despite this, we found that families are often keen to consent to tissue collection for research, even where post-mortem examination would not otherwise be undertaken.

In seeking consent, bereaved next of kin need to be provided with support and supplied with clear, factual and unbiased information, while respecting their feelings and wishes [3]. In addition to next of kin, close friends of the deceased sometimes wished to be involved in the consenting process. We found that a dedicated Bereavement Centre provided an appropriate environment for these discussions. The person seeking consent must have advanced interpersonal and counselling skills.

We attempted to minimize distress to bereaved next of kin by approaching only those considered by the bereavement officers to be most receptive to tissue donation, and by minimizing delays necessitated by the consenting process. Only limited data were collected in this study to explore the experiences of those families who did not consent to donation of tissues. As soon as it was suspected that relatives had reservations about tissue donation, the bereavement officers or study nurse moved away from providing further information about the study towards a more general bereavement counselling approach, and consent was not sought. Although this may have denied some relatives the possibility of contributing to the research, any further attempt to seek consent or a more detailed understanding of the relatives' reservations could have seemed coercive. Our findings suggest that relatives of deceased males were more likely to agree to meet with the study nurse, and consent to participation. This could either be due to an influence of gender on the researchers or on the relatives. Further studies would be required to determine whether participation can be predicted from demographic data such as age and gender.

In conclusion, we have found that post-mortem tissue collection for research remains feasible in the presence of a skilled, well co-ordinated, multidisciplinary team.

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Conflict of interest

The authors have declared no conflicts of interest.

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