Education and debate

Effect of media portrayals of removal of children's tissue on UK tumour bank

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Analysis of newspaper reporting shows how media scandals can affect scientific research, even when the research is not directly linked to the scandal

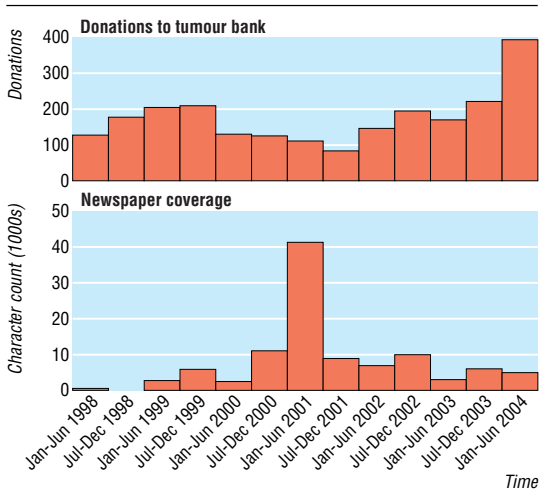
The consequences of controversies surrounding organs removed and retained from children after post-mortem examination in the United Kingdom[1 2] have been felt in diverse areas. The most obvious of these is pathology. Morale and recruitment of pathologists have been adversely affected,[3 4] and rates of autopsy have fallen from already declining rates.[4] Beyond pathology, levels of organ donation for therapeutic purposes such as transplantation have also fallen.[5–7] Such effects may occur because, fuelled by mass media reporting, the public does not readily distinguish between organ retention and other uses of human tissues.[8] Might there be links between media reporting and donation of tissues from children for ethically approved scientific research?

Tumour bank

The UK Children's Cancer Study Group tumour bank, established in 1998, provides a national network of stored tissue samples from children with cancer treated at the 22 group centres. Tumour banks rely on donations of tissue, taken with appropriate consent, to conduct biological research aimed at improving diagnosis and treatment of cancer. Samples are obtained at the time of diagnostic or therapeutic interventions. Registration of a tissue sample requires several steps and resources, including a trained healthcare professional to approach families for consent, a pathologist with appropriate technical support to identify and store tissue, and administrative support. Researchers may apply to use samples in research projects in childhood cancer. Each project is scientifically reviewed and must be approved by a multicentre research ethics committee.

Role of the UK press

We explored the role of UK newspapers in reporting and generating controversies relating to removal of human material from children for research purposes and the association of such reporting with rates of registrations of tissue in the UK Children's Cancer Study Group tumour bank. We used the search terms tissue/s, donation, child/ren, and research to search for national newspaper reports indexed since 1984 on Lexis-Nexis, a database of all UK newspapers. From 463 potentially relevant hits, we selected 122 articles that concerned the removal of human materials from children for biomedical purposes. Analysis of the news text yielded three major thematic categories (box) and subcategories; articles were also analysed for narrative structure. We wrote explicit specifications for thematic categories and used NVIVO qualitative software to code newspaper text. One person did all the coding (DK). A second person (CS) independently coded a sample of 20% of the articles, and disagreements were resolved through discussion between DK, CS, and MDW. We examined the relation between the number of registrations with the tumour bank in each six month period and newspaper coverage in the preceding six months from January 1998 to June 2004.



Donations to UK Children's Cancer Study Group tumour bank and newspaper coverage of use of human tissue, 1998-2004

Further data are on bmj.com

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Major thematic categories used for coding newspaper text

Direct harm—Reports of harms to individuals associated with removal of human material from children:

Sitting in her house full of the toys and clutter of three boisterous children, [a mother] shakes her head wearily. She can barely believe she has to go through this again. She is driven by the awful compulsion shared by many parents whose lives were turned upside down by the Alder Hey scandal. Some have spent years tracing and reclaiming organs retained without permission after post mortems on children who died years ago ... . The reburial ceremonies are harrowing but [she] knows she will never rest unless she sees it through.

Express 23 June 2002

System harm—Reports of damage to the healthcare system or systems for medical research associated with removal of human material from children (including how such removal is portrayed).

The body parts furore triggered an irrational and emotional backlash against pathology and organ donation, the effects of which are still being felt. A recent survey published in *New Scientist* found that one in ten pathology posts is vacant, as doctors shy away from joining a profession so widely caricatured as ghoulish. Scientists investigating severe diseases say their supply of samples has fallen by 90 per cent, and ethical review panels are rejecting studies for fear they will be misconstrued.

Times 6 December 2003

Benefit—Positive outcomes for individuals or society associated with the removal of human materials from children, including research and education:

[Organs or tissue from 88 babies] were used for Professor Fleming's study of Sudden Infant Death Syndrome which was published in 1992. Professor Fleming, whose work has been supported by TV presenter Anne Diamond, is credited with saving many lives through the recommendation that babies should sleep on their back, not their stomach ... We come into contact with some parents who say they were pleased that organs were kept and hope they are used for research which will find out what causes cot death.

Mail 20 April 2002

How the story about tissue retention developed

The earliest story meeting our selection criteria occurred in 1985, and less than four articles a year were published up to 1998. In late 1999, with the breaking of the organ retention story, coverage increased greatly. Even though we used donation rather than retention as a search term, most articles after this period concerned retention of children's organs (see table A on bmj.com), showing that it dominated reporting of use of children's tissue for research. Broadsheet coverage was roughly twice that of tabloid newspapers (table). Individual tabloid articles were significantly more likely to describe direct harm ($P < 0.01$). Sources used by journalists described a variety of benefits, therapeutic benefits being the most commonly mentioned (see bmj.com for further details).

The organ retention story rapidly acquired the characteristic features of a media scandal.[9] Particular actions and activities that were deemed to have offended community morality were made public. Crucially, these were formed into a narrative, whose central plot was the violation of dominant moral codes by a scientific establishment that should have been beyond reproach and the consequent harm to people already made vulnerable by bereavement. The discovery of organ retention was depicted as renewing and reviving the grief and shock that bereaved families had already endured, creating new forms of suffering. Repeat burial stories were portrayed as a series of aftershocks that revived feelings associated with bereavement:

[She] was back at the same graveside, feeling the same searing anguish, a mother forced to grieve all over again by a medical practice that now seems so cruel and arrogant that it beggars belief. For the infant that [she] laid to rest in 1985 was incomplete.

Daily Mail 13 May 2000

Like other media health scandals,[10] the organ retention story gained particular power by generating a series of oppositions. A fundamental opposition was that between victims (bereaved families) and the medical and scientific community, which was portrayed as the disgraced perpetrator of inexcusable wrongs. Further oppositions were created between family vulnerability and medical power, emotions and science, and voluntary giving and removal without consent. This kind of reporting sought to polarise the emotional response to the scandal between victims and perpetrators:

I did not want to donate any of the organs and I did not give consent for a postmortem. I just did not want anything done to her at all. We accepted that there had to be a postmortem for the inquest, but until recently I had no idea that they had removed any organs or kept them in storage. How could he butcher my daughter and take all of her organs?

Guardian 4 December 1999

Additionally, the organ retention narrative came to operate as a news template,[11] enabling a continuing narrative to be imposed on fresh news stories about the use of human materials from children, whether or not these directly concerned organ donation. In effect, everything to do with body parts and tissues was incorporated into the organ retention template. Thus, in January 2001, a story about the routine removal of thymus glands from children during heart surgery was depicted as repeating the errors of organ retention.

Attempts to disturb the news template became obvious from late 2002 onwards as the potential for government regulation to damage medical and research efforts was increasingly reported. Much of the positive coverage was associated with attempts by

Comparison of reporting of harms and benefits of tissue donation in broadsheet and tabloid newspapers (n=122 articles)

	No of articles (text character count)*		
Category	Tabloid	Broadsheet	Total
Direct harm	24 (17 365)	40 (16 195)	64 (33 560)
Benefit	20 (14 054)	56 (34 660)	76 (48 714)
System harm	14 (9081)	34 (20 377)	48 (29 458)
Total	36 (40 500)	86 (71 232)	122 (111 732)

*Text characters were assigned to mutually exclusive categories (direct harm, benefit, system harm). Newspaper articles could contain text from more than one of these categories. The total number of articles shown in the last row of the table is therefore lower than the column totals.

medical sources to repair the effects of the organ retention scandals.

What happened at the tumour bank

Both newspaper coverage and tissue registrations with the tumour bank varied greatly from 1998 to 2004 (figure). The number of registrations in each six months was inversely related to the newspaper coverage in the preceding six months. Using generalised estimating equations,[12] we estimated that each additional 1000 characters of newspaper coverage in a six month period was associated with a fall of 2.6 (95% confidence interval 1.7 to 3.6, $P<0.001$) registrations with the tumour bank in the following six months. This negative association remained significant after we had excluded outliers, changed assumptions about the grouping of time periods, and allowed for a non-linear relation between newspaper coverage and tumour bank registrations. We could not formally quantify separate effects for the different categories of newspaper coverage because they were so highly correlated.

Summary points

UK controversies about use of children's tissue have adversely affected the morale and recruitment of pathologists, rates of autopsy, and organ donation for therapeutic purposes

The organ retention story fitted a classic media scandal narrative and new events were portrayed as similar to the original story

Newspaper reporting blurred boundaries between donations from living children and those who had died and between different uses of tissues.

The intensity of media coverage was associated with a downturn in registrations of tissues in a national tumour bank

Medical staff may have been deterred from asking for donations by the negative publicity

Polarised views

The UK organ retention controversies were associated with greatly increased newspaper coverage of issues related to removal of human materials from children for research purposes. The raised intensity of media interest from late 1999 onwards was associated with a fall in registrations of tissue in a national children's tumour bank, showing how the controversies affected unrelated areas of use of human materials. In contrast with practices in the organ retention controversies, the tumour bank receives donations of tumour tissue from living children with appropriate consent and ethical approval. Newspaper reports blurred the boundaries between the use of materials from living children and those who have died; different types of materials (whole body parts and tumour tissue); and different uses of material. During the height of the controversy, press reports suggested that the only proper response to any use of children's tissue was scepticism and questioning of professional motives.

Families' unwillingness to donate is unlikely to have been the sole cause of the decline in donations to the tumour bank. Our previous analyses have shown significant dissonance between media reports and families' accounts of illness[13] and, in fact, very few families have ever refused to make a donation to the tumour bank. Our anecdotal experience is that staff became less willing to request donations to the tumour bank during the scandal, a response also noted in relation to adverse media coverage of organ donation.[14] Registrations began to recover towards the end of our study period, when medical sources attempted to restore public confidence and the scandal began to wane. Our findings show that media reporting of science can have important implications for those who conduct and regulate science.

Contributors and sources: CS, MDW, and DK are experienced in the analysis of mass media content. MT and PB are experienced in statistical analysis. RG and KP-J are experienced in managing the children's cancer tissue bank. CS participated in the design of the study on which this article is based, collected and analysed data, and led the writing with MD-W, who led the study and analysed data. DK, MT, PB, and KP-J participated in the design of the study, analysed data, and participated in writing the article. RG collected and analysed data and participated in writing the article. CS is guarantor.

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Competing interests: KP-J heads the UK Children's Cancer Study Group tumour bank and RG chairs the group's biological studies division, which approves projects accessing tissues from the bank. As such, they both have an interest in promoting public understandings of tissue donations to support research into childhood cancer.

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