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SHORT REPORT

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Accuracy of a history of blood donation from surrogate witnesses: data from the UK TMER study

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Look-back studies of blood transfusion in Creutzfeldt–Jakob disease commonly rely on reported history from surrogate witnesses. Data from the UK Transfusion Medicine Epidemiology Review have been analysed to determine the accuracy of the blood donation history provided by the relatives of cases. Our results show that only a small percentage of cases were found to be registered as donors on UK Blood Service (UKBS) databases when there was no family report of blood donation. In contrast, a history of reported donation was less accurate.

Key words: donors, epidemiology, prions.

Background

As part of UK national Creutzfeldt–Jakob disease (CJD) surveillance details of blood donation history are routinely sought through interview with family members and have been obtained in the great majority of cases [1]. Patient identifiers in all variant CJD (vCJD) cases eligible by age to donate (aged 17 and above) are notified to the UK blood services (UKBS) at the time of diagnosis to check whether the individual had ever donated. For other forms of CJD, identifiers are normally forwarded to UKBS twice a year and only for those cases with a reported history of blood donation.

Methods

All sporadic CJD (sCJD) cases, regardless of reported history of blood donation, who died between 2010 and 2016, were checked against the relevant UKBS database based on residence at diagnosis (NHS Blood and Transplant for England, Welsh Blood Service for Wales, Scottish National Blood Transfusion Service for Scotland and Northern Ireland Blood Transfusion Service for Northern Ireland). Data on previous UKBS checks for all vCJD cases old enough to donate, and only those sCJD cases whose families reported a history of donation, were already available. The actual blood donation data from UKBS were then compared with the information provided by relatives on donation history for both sCJD and vCJD.

Results and discussion

To date, there have been 178 cases of definite or probable vCJD identified in the UK. Of these, 168 were eligible by age to donate and their identifiers were sent at time of diagnosis to all four national blood service centres for checking. Between 2010 and 2016, 671 cases of sCJD had died in the UK (data ascertained as at 15 December 2016). All 671 were aged 17 or over, and their identifiers were sent retrospectively to the relevant blood centre based on residence at diagnosis (Table 1).

For the purposes of this study, unlike the procedure in place for vCJD cases, we sent sCJD cases only to the national blood service relevant to residence at diagnosis. This could be a potential limitation of the study as some cases moved between countries during their lifetime.

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Table 1 Demographics of 671 cases of sporadic CJD in the UK

Residence at diagnosis	sCJD deaths 2010–2016	Blood Service involved in checking for donor records
England	554	NHS Blood and Transplant (NHSBT)
Wales	43	Welsh Blood Service (WBS)
Scotland	55	Scottish National Blood Transfusion Service (SNBTS)
Northern Ireland	17	Northern Ireland Blood Transfusion Service (NIBTS)
Outwith UK[a]	2	NHS Blood and Transplant (NHSBT)
Total	671	

[a]Two cases diagnosed outside the UK had previously lived in the UK and were repatriated to the UK after diagnosis. Their last known address in the UK was used.

Figure 1a shows the overall results of the UKBS national databases search for UK vCJD cases.

Four vCJD cases (3%) were found to be registered as donors from 135 vCJD cases where there was no family report of donation. On further checking, components from only one of the four cases were issued. Families reported a history of donation in 12 vCJD cases who were not found on UKBS databases. Of these, seven were reported to have donated pre-1990, three after 1990 and in two the family originally reported them not to be blood donors, later changed their mind after discussion with wider family members, but details were unclear.

Figure 1b shows the overall results for UK sCJD cases searched by relevant national database based on residence at diagnosis. Eleven sCJD cases (3%) were found to be registered as donors from 433 sCJD cases where there was no family report of donation. Families reported a history of donation in 114 sCJD cases who were not found on UKBS databases. Of these, 46 were reported to have donated pre-1990, 36 from 1990 onwards, in 23 the family were unsure of donation dates and nine cases were reported to have donated outside the country where their donation records were searched. Of these nine, two were reported to have donated outside the UK, six in the UK but in a different country from their residence at diagnosis and one case was reported to have donated on board a ship.

Conclusions

The low percentage of cases (3% in both vCJD and sCJD) found by UKBS to be blood donors when there was no family report of blood donation is reassuring and implies that reported data on the absence of blood donation are relatively accurate. There was a slightly higher percentage of sCJD cases (5%) found by UKBS to be blood donors

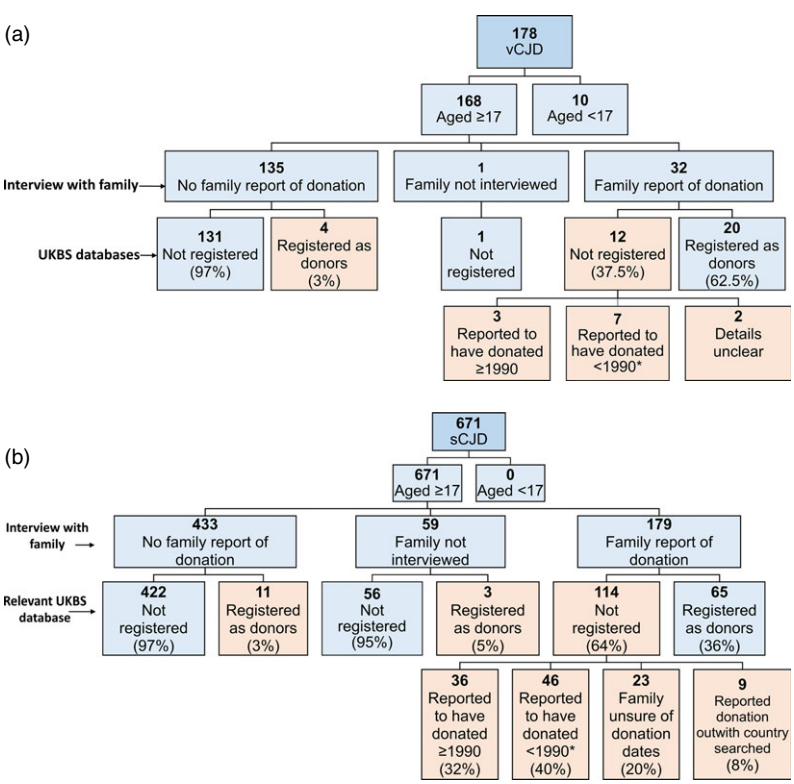

Fig. 1 (a) Variant CJD (vCJD). (b) Sporadic CJD (sCJD). *The data for blood donation pre-1990 are incomplete.

where no information was available on donation history (i.e. family not interviewed). The higher percentage of sCJD cases (64%) not found on national blood service databases when there was a family report of blood donation is most likely due to donations pre-dating available records; the older age at diagnosis suggests they may have been donors before the national databases were compiled (approximately 1990 in NHSBT, which accounted for the great majority of searches). In a small number of cases, donations were made in a different country from the residence at diagnosis.

Look-back studies in CJD [1–3] are unlikely to obtain complete information on blood donation history from family members and checking donation history through other sources may improve the accuracy of these studies.

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References

1 Urwin PJ, Mackenzie JM, Llewelyn CA, *et al.*: Creutzfeldt-Jakob disease and blood transfusion: updated results of the UK Transfusion Medicine Epidemiology Review Study. *Vox Sang* 2016; **110**:310–316

2 Dorsey K, Zou S, Schonberger LB, *et al.*: Lack of evidence of transfusion transmission of Creutzfeldt-Jakob disease in a US surveillance study. *Transfusion* 2009; **49**:977–984

3 Puopolo M, Ladogana A, Vetrugno V, *et al.*: Transmission of sporadic Creutzfeldt-Jakob disease by blood transfusion: risk factor or possible biases. *Transfusion* 2011; **51**:1556–1566