Cautionary Tales

in Organ Donation and Transplantation Clinical Governance Team, ODT

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Many of you will have heard of 'Learning from Excellence'. I am pleased to share that we now have a route through ODT for all working within organ donation, organ retrieval and transplantation, both internal to ODT and external, to highlight excellence within the pathway.

In general, everyone comes to work to do a good job; but traditionally the focus has been on the small percentage of times when something goes wrong, rather than the significant percentage of when it goes well, or when people go over and above.



Whilst we do still need to look at when things go wrong and what we can learn, it is equally important to identify and

capture excellence in the pathway. We know that excellence can create opportunities for learning and enhance staff morale by sharing positive feedback.

Please share the link below with your colleagues and encourage to submit:

https://www.odt.nhs.uk/odt-structures-and-standards/governance-and-guality/learning-fromexcellence/

Histopathology – Work in progress but there is progress!

It is accepted that there is an urgent need to strengthen histopathological support for organ & tissue donation and transplantation in the future. Whilst we had anecdotal information, a pathologist survey in summer 2018 indicated that the service was not consistent or sustainable across all transplant centres.

There is a clear commitment from all involved to find solutions to stabilise the service and Professor Derek Manas is working with key stakeholders, including laboratories and ODT commissioning to do this. A meeting recently took place to review options with the aim being to understand from all parties involved what would be needed to design a robust and sustainable service UK wide. Whilst it is very early days, there were a number of options put forward that are being explored currently.

Whilst the availability is a known issue, this is not the only concern that has been highlighted; following a number of incidents related to the pathway, a small group of key stakeholders have developed a guidance document for suspicious lesions identified at time of retrieval. Following support at the Retrieval Advisory Group this was implemented and has proved to be a success; reported issues around this area have reduced. Following this implementation, a trend in the reports received relating to when suspicious lesions are identified at the accepting centre were highlighted. The concerns raised were that:

- An organ was disposed of without taking a biopsy (if the centre chose not to transplant).

- A biopsy was taken but processed as 'routine' which prevented results being available to centres that wished to know the result prior to transplantation.

- An organ was transplanted without a biopsy being taken due to the risk-benefit of that organ transplant; however other centres would have requested a biopsy to enable the transplant to proceed.

- Biopsies being taken but this information not being communicated to ODT Hub Operations or other centres.

- Results of a biopsy being sent to ODT Hub Operation without donor ID which does not allow for onward dissemination.

A small group of key stakeholders were again brought together to review and develop a pathway for when suspicious lesions are identified at a transplant centre. This pathway was disseminated via all Organ Advisory Groups and following minor changes was fully supported. This became available on the 27th January 2020 for centres to review and has been circulated to key stakeholders.

https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17576/new-findings-made-attransplant-centres-requiring-histopathology-assessment-sop5735.pdf

https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17577/national-histopathologyrequest-form-frm6390.docx

Please take the time to review this process to ensure that all involved are aware of the steps agreed nationally.

And then there's routine histopathology...

When a suspicious lesion is identified, it is hoped that it is accepted as standard practice that this information is communicated quickly, as people are aware of the potential implications. There have however been a number of cases that have identified the importance of following up results when samples are sent for 'routine' histopathology; as in there was nothing identified on visualisation, but it is standard practice at that centre to send the tissue for histology.

One example of this was a renal centre performed an excision of a lesion on a kidney prior to implantation. The lesion was small and thought to be non-suspicious therefore the kidney was transplanted into the recipient prior to receiving the result. The results were not followed up and a year later an internal audit took place at the transplant centre and the result was highlighted; this showed a clear cell carcinoma in the donated kidney. The situation was reviewed by the multi-disciplinary team who reassured the other accepting centres that the risk of spread to other organs was near negligible. No transmission has been reported to date.

Another example was in relation to a simple cyst on a kidney. At the accepting centre, as part of the preparation they "deroofed" (removed the top of the cyst) the kidney cyst and as per their usual practice sent the tissue to the laboratory for routine histopathology. On receipt of the report a number of weeks later it concluded that the biopsy showed a "multi-cystic renal neoplasm of low malignant potential". This information was provided to Hub Operations and subsequently forwarded to all appropriate centres. At least one of the transplanting centres then altered their patient's immunosuppression based on this information.

The two different cases above highlight how routine testing can identify unexpected results. The second case highlights how, by ensuring these results are followed up and communicated to other centres in a timely manner, patient management can be altered to ensure the transplant process is a safe as possible.

Learning point

- There is ongoing work reviewing the availability of histopathology services as it is acknowledged how this can impact on organ utilisation and patient safety.
- Whilst availability is a longer-term resolution, there are key things in the short term that can be done to strengthen the current situation; and there is now clear guidance for all involved for when suspicious lesions are identified both during and after retrieval.
- It is vital that as well as the results of suspicious lesions, the results of non-suspicious samples from donated organs that are sent for routine histopathology are followed up in a timely way; any results which may impact on the management or treatment of other organ and/or tissue recipients must then be communicated to Hub Operations to allow onward dissemination.

World of Social Media and Confidentiality

Telling someone they are about to receive a lifesaving or changing transplant can be an emotional time. Patients may have questions about the potential donor and multiple factors may lead to information being provided over and above the standard. Whilst it is understood how this may happen, it is important to ensure that anyone who may discuss organ offers with patients are aware of the donor information they can provide.

In a recent case it was highlighted that a recipient had included a large amount of information regarding their donor on twitter. The redacted parts in the snap shot indicate the information present that could potentially identify the donor; the exact age was included along with a significant amount of detail around the circumstances of the donor's death.

Due to the quick actions of those involved, this was discussed with the recipient and the information was subsequently deleted. They posted as they were grateful for their gift and never meant to upset. The donor family were also contacted to (to note, the twitter account details and recipient hospital have been redacted on this snap shot to ensure anonymity of the recipient). inform of the information breach and were fully understanding of the situation.



The twitter account details and recipient hospital have been redacted on this snap shot to ensure anonymity of the recipient.

In the new world of social media, this highlights how easy it can be for information to be linked and is a reminder to be mindful of information given.

Learning point

- Information that can be provided to the potential recipient regarding the donor include:
 - Age range, so patient in their 40's rather than 42
 - Gender
 - Type of death (unless it compromises confidentiality); consider how much information around the circumstances of death are given.
 - Whether there is greater risk of transmissions of infection or malignancy
- The full policy regarding this can be found here: <u>https://nhsbtdbe.blob.core.windows.net/umbraco-assets-</u> <u>corp/4378/guidelines consent for solid organ transplantation adults.pdf</u>

Retrieval in a Hepatitis C Positive Donor

Whilst no retrieval is the same, they generally all follow a fairly standard path. There are occasions though when things proceed quite differently. The next case was unusual and is not likely to be quickly repeated, however due to the impact and uncertainty it was felt beneficial to share.

The NORS team were mobilised to a known Hepatitis C (HCV) positive donor; both kidneys had been accepted. Upon arrival the NORS surgeon raised concerns around the coagulopathy (abnormal clotting) in light of the positive virology result and requested further bloods were sent.

The repeated clotting results showed the donor had worsening coagulopathy; the NORS surgeon was uncomfortable proceeding in the presence of uncorrected coagulopathy and the associated bleeding risk in a Hepatitis C positive donor. Following conversation with the Clinical Team a decision was made to transfuse FFP and platelets. The process of awaiting results and locating platelets led to a 6-hour delay to retrieval.

Whilst on reflection the NORS team felt they would not change their management if the situation arose again, they also raised that as the utilisation of organs from Hepatitis C positive patients is likely to increase, more guidance would be welcomed.

Due to the uniqueness of this case a second review was completed by the Chair of the Retrieval Advisory Group and the below guidance has been provided;

- 1. The closest parallel to this situation is hepatectomy in HCV+ viraemic patients with liver failure. Such may receive platelets and factors in the immediate pre-operative phase, but this may not be required until after the operation has commenced. Bleeding in such patients generally relates to 'raw areas' created during mobilisation rather than coagulopathy per se.
- 2. There is no absolute need for pre-op platelets or factors, but it is likely that an anaesthetist would have factors/platelets available (as with any surgical procedure in a coagulopathic patient). A decision should be made collaboratively with the anaesthetist before surgery. If it is felt products are required, this should not delay retrieval, nor should there be any need to check laboratory investigations of coagulation once factors have been given. In fact, the time delay involved in such testing allows the effect of factors to wear off.
- 3.It is essential to minimise transmission risk in HCV+ donors. Full PPE including eye protection is required for any retrieval process. If desired, the use of sharps can be minimised (open with diathermy). Transmission risk logically relates to penetrating injury rather than the volume of blood loss. Therefore, bone fragments generated during sternotomy are likely to be the major risk to staff. Correction of coagulopathy would not change transmission risk in the event of a sharp injury in this case.

Learning point

- It is accepted that this was a rare situation and those involved made decision based on what they felt was the safest for all involved.
- Following significant review, the above points have been provided to guide teams in their decision making if faced with this situation.

If you have any feedback or suggestions regarding Cautionary Tales or Learning from Excellence please let us know via email: <u>Jeanette.foley@nhsbt.nhs.uk</u>

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