**Title**: Parents’ experiences of requests for organ and tissue donation: The value of asking

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**ABSTRACT**

**Objective**: A proportion of children die, making them potentially eligible to be organ/tissue donors. Not all are approached for donation, and experiences of those parents are not well understood. The objective was to investigate to what extent organ and tissue donation is discussed as part of end-of-life care and to explore parents’ and health care professionals’ (HCPs) experiences.

**Design**: A retrospective qualitative study

**Setting**: Multicentre study with participants recruited through two neonatal intensive care units (ITU), two Paediatric ITUs, a Cardiac ITU and a children’s hospice.

**Patients**: Bereaved parents, parents of a child with a long-term condition (LTC) and HCPs.

**Interventions**: none

**Main outcomes and measures**: Parents’ and HCPs views and experiences of discussions about organ and tissue donation.

**Results:** 24 parents of 20 children were interviewed: 21 bereaved parents and 3 parents of a child with a LTC. Seven parents were asked about donation (13 not asked), 4 agreed, 2 donated. 41 HCPs were interviewed. Themes: complexity of donation process, OTD as a coping strategy, the importance of asking, difficulty of raising the topic, and parents’ assumptions about health of organs (when donation is not discussed).

**Conclusions:** The findings add new knowledge about parents’ assumptions about the value of their child’s organs when discussions about OTD are not raised, and that HCPs do not routinely ask, are sometimes hesitant to ask in fear of damaging relationships, and the reality of the complexity of the donation process. Given the current levels of awareness around OTD, the topic should be raised.

**What is known about this topic**

Parents’ experiences of discussions of organ and tissue donation (OTD) have been investigated. Experiences of parents whose child was not eligible have not been investigated.

**What this study adds**

When OTD is not raised, parents can make assumptions about the value of their child’s organs. Donation should be discussed, regardless of eligibility for donation.

**Introduction**

Paediatric organ and tissue transplantation is an accepted lifesaving intervention. Ongoing campaigns have raised awareness about organ and tissue donation (OTD). Providing family members with the option of OTD is often an element of end-of-life (EOL) care.[1-5]

Factors that facilitate positive perceptions of OTD and willingness to consent include awareness OTD, initiation of a conversation, adequate time for discussion, and sensitive and compassionate staff.[6-9]Consenting to donation can have a positive influence on bereavement.[10,11] Equally, negative feelings have been reported, which can be mitigated by more information about EOL care and the process of donation, and compassion from staff.10

Parents consent to donation through a desire to help others, believing it is ‘the right thing to do’ and believing that through donation their child is able to live on in others.[12] Reasons to refuse donation focus on concerns about the child having suffered enough, fears of mutilation of the body, and overwhelming grief.[12]

Research to date has focused mainly on the experiences of parents and families who have been approached for donation, [6,8,10-15] and thus were eligible for donation. However, there is evidence that despite policy guidance, opportunities for donation are being missed.[16-18]

The current investigation has been shaped by these factors: 1) opportunities for OTD are missed, 2) discussions about OTD should be part of paediatric EOL care, 3) campaigns have raised awareness, and 4) studies to date have focused on children eligible for OTD. Therefore, we explored whether OTD is discussed with parents of children with a life-limiting condition, irrespective of eligibility, and what their experiences were. In addition, we explored the views of health care professionals (HCPs).

## **Methods**

## The data presented here are part of a larger qualitative interview study with bereaved parents and parents of a child with a life-limiting/threatening condition, exploring experiences of quality of EOL care, parental coping, and OTD. In the current manuscript, findings around discussions about OTD are reported.

## The study took place in two large academic hospitals and a children’s hospice in the UK. Key recruitment pathways were via: two neonatal intensive care units (ITU), two Paediatric ITUs, one Cardiac ITU, and a children’s hospice.

## Parents were interviewed. In addition, focus groups and individual interviews (where participation in a focus group was not feasible) were carried out with HCPs to explore their experiences of discussing OTD.

**Participant selection and recruitment**

Parents were identified through the clinical teams. Parents who had lost a child in 2013 or 2014 (with a small number in 2011 and 2012) were approached and parents were excluded if there were particular issues that were raised about the child or family. These would include difficult interactions with the clinical team, court cases or other difficulties that were sensitive. We did not record the number of families excluded or the specific reasons. Every effort was made to avoid contacting parents near significant dates such as birthdays, and Christmas.

Parents identified by clinicians at the participating units were sent a study invitation letter and information. If parents were willing to consider being involved in the study they could respond by: i) returning the included reply slip, ii) contacting the researcher by e-mail/phone, or iii) contacting the identified nurse specialist on the given unit. A positive response was followed-up by the researcher. Parents were given at least 24 hours to think about participation.

Key HCPs, from a variety of backgrounds (e.g. consultants, nurses, family support workers), were recruited from the participating. HCPs were invited from the participating units and the hospice and an attempt was made to organise focus group discussions around team meetings (to increase participation). Purposive sampling was used to include a wide variety of clinicians, with adequate representation from doctors and nurses.

**Procedure**

Parents were interviewed via a telephone call, a method previously used in research around OTD [19,20]and bereaved parents.[21] Consent was gained at the start of the interview, by parents verbally consenting to a series of statements, which were audio-recorded. Parents were asked if OTD had been discussed with them and their experiences of this. An interview schedule was used, which also incorporated questions related to quality of care and coping strategies (as part of a larger study. The topic guide was developed based on the current literature and the team’s clinical and research expertise. New questions were not added to the topic guide as the interviews were conducted.

An appropriate HCP was available for support if parents became distressed. All interviews were conducted by a HCP/researcher with extensive palliative care experience. The interviews were transcribed by a professional transcriber.

HCPs were interviewed in focus groups facilitated by two researchers, and individual interviews. HCPs were asked about whether they raised the option of OTD and what their views and experiences were around this.

All interviews were audio recorded and transcribed. Ethical approval was gained through the University of Southampton, the UK Integrated Research Application System (IRAS; 15/SC/0492), the children’s hospice ethics committee, and hospital R&D departments.

## **Analysis**

The transcripts were thematically coded by two members of the research team (DR and VR) independently. The data was organised using Nvivo software [22] following the principles of thematic analysis.[23].A preliminary coding list was developed inductively with further iterations of the master code list developed. Codes were grouped and compared. The coding assumptions of the two researchers were evaluated separately by a third member of the team (ASD) and codes and themes agreed. Activities to enhance rigour included the development of an audit trail of all meetings, review of coding notes and iterative discussions. Overlapping themes were also identified between the parent and HCP interview coding lists.

## **Findings**

## **Participants**

## *Parents*

104 parents were approached to participate, 39 (37.5%) from NICU, 39 (37.5%) from PICU, 10 (10%) from CICU and 16 (15%) from the children’s hospice. The majority were bereaved parents with seven parents approached while their child was alive. Twenty-six parents of 26 children (25% response rate) responded and indicated that they were potentially interested in the study. A total of 24 parents of 20 children were interviewed: 21 bereaved parents and 3 (43%) parents of a child with a life-limiting/threatening condition (Table 1). Seventy percent were mothers. Seven fathers were interviewed either as part of a couple or as individuals. Children had a range of diagnoses, such as a brain tumour, spinal muscular atrophy, preterm birth with brain damage and cerebral palsy, and congenital cardiac conditions.

*Healthcare Professionals*

Four focus groups; one with critical care nurses, one with critical care physicians, one with palliative care HCPs and one with hospice staff, and three individual interviews (with hospice staff) were carried out. A total of 41 HCPs were included, with 14 doctors (34%), 24 nurses (59%) and 3 allied health professionals (e.g. family support worker 7%).

TABLE 1 ABOUT HERE

## **Discussions about organ and tissue donation**

## Seven families (7/20; 35%) were asked about OTD. This included parents who initiated discussion about donation before staff raised the topic. Four agreed to donate their child’s organs and two were successfully able to do so.

Many parents shared positive views about OTD, regardless of whether discussions were had or not with them, including that OTD made them feel proud (‘*gives me something else to be proud of for him … and save four other lives’ (01ICU)*, the thought of donation as a positive thing for a parent who did not donate (‘*I’ve almost thought in a way that’s quite a nice thing because you feel that a part of your child has gone on to help another child*’ (*08ICU*), the need to do it to help others *(‘ .. if I can help another family to avoid something like this I’ll do it*’ *(13HOSPC*)) and the thought of the organs living on in someone else *(‘ .. they are still out there, it’s amazing’ (01ICU*).

## Below we describe the experiences of parents who were asked about donation (Section A), parents who were not asked (Section B) and HCPs (Section C).

## **Section A: Parents who were asked about donation**

The main themes (Table 2) included the factors underpinning their decision-making, complexity of the donation process, and quality of the care and staff.

**Factors underpinning decision-making**

Factors underpinning parents’ decision-making included already knowing they wanted to donate their child’s organs, prior experience with donation and having an increased understanding of the importance of donation. Factors leading to declining donation included just knowing this is something they did not want for their child, OTD having the potential to interfere with other EOL choices (e.g. holding the child or taking the child home), and their child having been through enough.

**Complexity of donation process**

In terms of the complexity parents noted the negative aspects of the donation process which included neurological testing for brain stem death, onerous amounts of paper work, and the time it took to organise the procedure.

**Quality of care**

Parents emphasised the sensitive way the discussions about donation were raised and conducted, with parents able to ask any questions. Parents highlighted the dedication of HCPs, the respect that HCPs showed their child before and during surgery, and feeling reassured that they were in good hands.

TABLE 2 ABOUT HERE

## **Section B: Parents who were not asked about donation**

The two main themes were hypothesised responses and assumptions about the health of the child/their organs for donation.

**Hypothesised responses**

Some parents indicated that they would have had a positive response suggesting they would have been open to having the conversation and even welcomed it. Equally, some parents indicated that they ‘*didn’t think we would have coped’* if the topic of OTD had been raised, or that they would have ‘*wrestled with it’*.

**Assumptions about health of the child/their organs for donation**

A number of parents who were not asked about donation made assumptions about their child’s physical well-being, i.e. assuming that the reason they were not asked about donation was because their child’s organs were not ‘*good enough*’, the treatment had been too intense, organs not ‘*usable*’, or ‘*any good’*.

FIGURE 1 ABOUT HERE

**Section C: Health professionals’ views and experiences**

Four themes mirrored themes from parents, namely OTD as a coping strategy, complexity of the process, importance of asking, and parents’ assumptions about health of organs.

Four themes emerged (Table 3), specifically what happens in practice, raising the topic is difficult, different request, and choices at EOL influencing decision-making.

**Organ donation as coping strategy**

For some parents the opportunity of OTD can be seen as a coping strategy, by allowing parents to have a positive experience, and by giving meaning.

**Complexity of process**

The process of OTD can add another 8-10 hours onto the EOL pathway. HCPs reported that some parents initially agree and then change their mind due to this ‘*time lag’*, as the time lag is burdensome.

**Importance of asking**

Several HCPs highlighted the importance of asking, even if donation is not an option for those children. Some HCPs emphasised that it is important to ask as it can validate the child, and parents feel ‘*grateful that they were asked and it was meaningful to even be asked’.* HCPs indicated that parents should be given the choice to think about OTD and make a decision.

**Assumptions from parents**

Parents, and HCPs, often make assumptions about whether children can be donors, based on their underlying condition or treatment, and that often these assumptions are not correct.

**What happens in practice**

HCPs described that in some areas of practice, assumptions are made that 1) discussions about OTD will have taken place in other areas of practice or 2) that wishes may have been noted or in advanced care plan, or 3) that specialist nurses – organ donation (SN-ODs) will raise the topic. In addition, some HCPs expressed the view that the discussion about OTD is not raised often and is not asked routinely.

**Raising the topic is difficult**

HCPs acknowledged that raising the topic is difficult, especially if parents have not yet accepted or realised that their child is likely to die, or when HCPs have worked hard to develop rapport with parents. HCPs also highlighted that many conversations aim to offer support, whereas raising the topic of OTD felt more like a request.

**Offer of tissue for research purposes**

One different type of request was the request for the tumour to be removed in order to contribute to future research.

**Choices at end of life / decision-making**

HCPs reported that some parents make decisions at EOL which make OTD more difficult or not possible, for instance when parents choose to have their child die at home.

TABLE 3 ABOUT HERE

**Discussion**

The findings add new knowledge to our understanding of parents’ assumptions about the value and use of their child’s organs when discussions about OTD are not raised. In addition, the finding that HCPs do not routinely ask, are sometimes hesitant to ask in fear of damaging relationships and the reality of the complexity of the donation process which has the potential to interfere with other EOL preferences.

A very significant finding in this study related to parents who did not have discussions about OTD, is that when this topic is not raised parents can make assumptions about the reasons why, centred around the health or value of their child’s organs (e.g. child’s organs were ‘no good’, or unusable). To the best of our knowledge this study is the first to report this. We speculate that ongoing campaigns to raise awareness of the importance of OTD has had an influence. Rather than being surprised by a request, some parents may expect this discussion, and when the topic is not raised, they will speculate on what this means. This finding was reiterated by HCPs and particularly highlights the importance of starting to explore ways and means, and timing of raising the issue of OTD at end of life and exploring this with parents, to ensure that they are aware of the reasons why OTD may or may not be an option for their child.

The main findings from parents with whom discussions were held emphasise that the process of donation is complex and that they had a variety of reasons for declining or proceeding with donation, such as donation interfering with other EOL decisions, also mirrored in HCP interviews. Reasons for declining or proceeding with donation have been studied previously and highlight that parents hope to help others, believe it is ‘the right thing to do’ and believe that their child is able to live on in others,[12] similar to adult studies.[24] Reasons for declining to donate include concern about the child having suffered enough, fears of mutilation of the body, and overwhelming grief.[12].The current findings add to this by highlighting that among those approached for donation the complexity of the process has the potential to interfere with EOL decisions, thus leading parents to decline, even though they initially think positively about OTD. Importantly, parents highlighted the quality of staff and their dedication and sensitivity, which is echoed in other studies.[13,25]

HCPs in our study underscored that they felt that they did not raise the topic of donation as often as they should, and while they acknowledged that there is value in asking they did not find it easy to raise the topic. Current UK processes recommend discussions about organ donation ought to be deferred until a Specialist Nurse in Organ Donation is present and the optimal approach planned, an approach supported by our finding that HCPs prefer not to raise the topic, as they do not wish to compromise the relationship. Introducing the topic whilst caring for a dying child can sound like a request or can even be perceived as a desire to hasten death so that organs might be donated. Requests/conversations about donation are optimally deferred until ‘brain death’ testing is planned, or a decision with the family has been made to plan a one-way-wean of life sustaining therapy - in this way honouring even the strictest version of the dead donor rule that donation is in no way deterministic of decisions around death. However, it is important to state there is public and professional discourse about this.[26,27] These findings are in line with some of the conclusions of a recent scoping review which emphasises that communication with families should not solely focus on securing consent and maximising donation, but also focus on assisting the family to make choices.[28]

Limitations of the study include the inclusion of bereaved parents, which introduces a certain level of recall bias and bereavement interfering with the narrative around their EOL experiences. The sample of parents was also self-selective, as only 25% of parents expressed an interest in participating in the study. In addition, no information around eligibility for donation was collected for the children, which means the study cannot draw any conclusions about the number of children who should have been approached for OTD. However, was not the goal of the study to investigate this. Finally, due to its qualitative design the study findings may not be directly generalisable.

Future research should explore to what extent incorporating OTD as part of EOL conversations can facilitate quality care. In addition, a larger study should be carried out targeting all bereaved parents to understand whether they would have valued a discussion about OTD, regardless of eligibility. This data would inform communication strategies, which could include simple messages (e.g. children who die outside of an ICU cannot donate organs because when the heart stops the organs are irreversibly injured and are not suitable) while acknowledging the complexity around these issues. In addition, future work should explore parents’ knowledge and perceptions about the difference between organ and tissue donation, and the possibility for donation in different circumstances.

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**Contributorship Statement**

Dr Darlington conceived the study, contributed to the literature review, provided data, and carried out the qualitative data analysis.

Dr Long-Sutehall conceived the study, contributed to the literature review, and provided additional data interpretation.

Dr Randall and Ms Robinson carried out the qualitative data collection and analysis

Professor Wakefield contributed to the literature review and provided additional data interpretation.

Dr Brierley conceived the study, provided data, and provided additional data interpretation.

All authors reviewed results, reviewed and contributed to the report.

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Table 1. Parent and child characteristics

|  |  |  |
| --- | --- | --- |
| Parents | Mothers | Fathers |
| Parents, n (%) | 17 (70%) | 7 (30%) |
| Ethnicity, n (%) White British or European Asian Unknown | 16 (95%)1 (5%)0 (0%) | 6 (85%)0 (0%)1 (15%) |
| Highest Level of Education, n (%) Secondary Higher  Unknown | 3 (18%)13 (77%)1 (5%) | 0 (0%)5 (71%2 (29%)  |
| Employment  Full-time employment Part-time employment Homemaker | 1 (5%)13 (77%)3 (18%) | 7 (100%)0 (0%)0 (0%) |
| Living with Partner Partner and child(ren) Child(ren) Alone Other | 6 (35%)6 (35%)2 (12%)2 (12%)1 (6%) | 4 (60%)1 (16%)0 (0%)0 (0%)2 (29%) |
|  | Children represented |
| Deceased, n (%) | 17 (85%) |
| Recruited through, n (%)Neonatal Intensive Care UnitPaediatric Intensive Care UnitCardiac Intensive Care UnitChildren’s Hospice | 5 (25%)8 (40%)1 (5%)6 (30%) |

Figure 1. Themes from Parent and HCP interviews

Table 2. Themes/subthemes and representative quotes from parents

|  |  |  |
| --- | --- | --- |
| **Main themes** | **Subthemes** | **Representative quotes** |
| **Experiences of parents who were asked about donation** |
| Factors underpinning decision-making |  |  |
|  | Some parents know they want to donate their child’s organs. | *I knew I wanted to give his organs. I knew without, they didn’t even have to ask me, so that part of it was very quick. (01ICU)* |
|  | Prior experience of donation | *The reason being is my cousin had lost her husband…..brain dead and they had to turn the machine off and took his organs, so having gone through that with her. (01ICU)* |
|  | Declining option of donation | *At the time, we didn’t even need to look at each other, we both said, no thank you. (04ICU)* |
|  | Child has gone through enough | *And at the time, we didn’t even need to look at each other we both said, no thank you…For us, we just felt like he’d been mucked around with enough…It was a case of just leave my baby alone… I’m also glad we didn’t have anything else on top of that. And he was in a bit of a mess anyway. I didn’t like the idea of them messing up even more you know. (04ICU)* |
|  | Interfering with other decisions at end of life | *I think the only thing that really put us off and I can’t remember exactly …that maybe he couldn’t have died in our arms because they would have had to take him away so quickly or something. I think that was another reason that we decided not to because we wanted to spend some time with him afterwards and one of the things they said to us was that they would have to take him away straight away but we wanted more time with him. So that was another one of the reasons why we didn’t. (22ICU)* |
| Complexity of donation |  |  |
|  | Donation not an easy process | *I think he was pronounced dead on the 3rd but I don’t think he actually left the hospital until the 4th because of the organ donation thing, that took a bit of time actually, bless her. It’s not an easy process for the child. (01ICU)* |
| Quality of care / staff |  |  |
|  | Sensitivity of discussions  | *I liked them and they gave us a lot of info. I could ask all the craziest things that came to mind and they would answer, so that was good. (02ICU)**It was raised, but I think it was raised very sensitively. (14ICU)**They were very responsive and they sent one person from the organ donation service to us on the Sunday. We had this long conversation that I can’t recall at all, I was there but I was not there but I remember that they were very responsive and they sent in this person as soon as they could and they explained to us and took their time. I think they were very good with that honestly. (02ICU)* |
|  | Before and during surgery | *The compassion, the knowing that even though he’d done his brain stem and he was brain dead they still anaesthetised him. I knew 100% when they got him up on that table they were treating him with respect. (01ICU)* |
|  | Dedication of team | *… like I say the donor people were there for hours. He was supposed to go home from his shift but he said I’m not leaving you, he said I’m staying so he had to phone and get childcare or something and phone his wife and say he wouldn’t be home so it was a stress for everyone. (01ICU)* |
| **Experiences of parents who were not asked about donation**  |
| Hypothesised responses |  |  |
|  | Possible positive response | *I wouldn’t have been angered or anything like that if I’d been asked the question. (18HOSPC)**It was never discussed, but if it had been, then it would have been something we were open to, definitely, but as I say, we were never asked. (12ICU)* |
|  | Possible negative response | *Yes, thinking back I don’t think I would have (agreed to donation), and maybe someone somewhere assessed this for me but I don’t think I would have coped with someone asking me that at that stage because we’d been through a rollercoaster of 8 weeks. (17HOSPC)* |
|  | Ambivalence | *I would have wrestled with it because I know how much help it would have been to somebody else but we weren’t asked the question. (18HOSPC)* |
| Assumptions about health of child/organs for donation |  |  |
|  | Organs not good enough | *I couldn’t say because we never thought about it and to be fair our son was quite poorly in the end that I don’t think his organs would be good enough. (09ICU)* |
|  | Intense treatment | *Perhaps because he’d had such an intensive hit with radiotherapy and all the chemotherapy whether or not that meant that we couldn’t have used anything…..(08ICU)* |
|  | Organs unusable | *No they didn’t actually (ask about organ donation), I think because there was so much of her that went wrong, I don’t know if any of it would have been usable. (C)ouldn’t use her kidneys, couldn’t use her heart, I don’t know if any of the meds she was on would have affected her liver, I don’t know. But it was never discussed, but if it had been, then it would have been something we were open to, definitely, but as I say, we were never asked. (12ICU)* |
|  | Not any good | *Yes, although she was on life support, so she would have been in a position of being able to use then I presume, so I can only assume that they wouldn’t have been any good. (12ICU)**Yes, I kind of don’t think they’ll probably want hers. The rest of us are all on [the] organ donation register but no one has really brought it up with us but to be honest it’s all a bit knackered, her lungs are knackered, she’s epileptic, her kidneys are not the best, liver maybe I don’t know but I don’t know what kind of shape that is in. She can’t see very well so they’re not much good either…(16HOSPC)* |

Table 3. Themes/subthemes and representative quotes from health professionals

|  |  |  |
| --- | --- | --- |
| **Themes** | **Subthemes** | **Representative quotes** |
| Organ donation as coping strategy |  | *It’s interesting so for them the coping was knowing that turning it into a positive that they’d lost their beautiful daughter but she was giving life to six people. (01HCP)* |
| What happens in practice |  |  |
|  | Discussions about donation occur elsewhere | *The conversations tend to happen before they come here. (01HCP)**We don’t tend to have those conversations. (01HCP)* |
|  | Not routinely asking | *…we certainly don’t ask anywhere near the numbers that we should because even if they cannot donate organs or tissues I think we should ask but I think we don’t really give them the opportunity’* *(05HCP)**I think we don’t ask. We certainly don’t ask anywhere near the numbers that we should. (05HCP)* |
| Raising the topic is difficult  |  |  |
|  | If parents have not accepted that the child is dying organ donation is difficult to talk about | *Goes back to how they have accepted what is happening with the child. If parents have not accepted that the child is dying then it is very difficult to talk about organ donation. And I don’t know what they would say in that situation, whether it would help them accept it or not, but it is very difficult to raise it at that point. (06HCP* |
|  | Asking is difficult once rapport has been created | *I think it is really hard to ask and I don’t really want to be the one who brings it up, when you have created a rapport with that family and having that conversation. (06HCP)* |
|  | A request versus an offering | *Organ donation still seems more like a request than an offering. (06HCP)* |
| Complexity of process |  |  |
|  | Process of organ donation takes a long time | *The flipside is that the process of organ donation is so long, it is a long time for parents to have to wait, they’ve made the decision and sometimes 8 to 10 hours. (07HCP)* |
|  | Parents change their mind because of time | *Yes this is what he would have wanted.. he has told us this and then we got to this thing of the time delay and whole thing flipped on its head….they couldn’t cope with that time lag…in the same conversation thinking about what he [child] would have wanted and then immediately flipped to ….they couldn’t deal with that time lag. (07HCP)* |
| Different requests |  | *Some families have asked about donating the tumour to research afterwards. (05HCP)* |
| Choices at end of life / decision-making etc |  | *The other one is some families will ask about tissue donation or something but then not proceed with it because they’ve chosen to have a death at home and don’t want the certain timescales to be on call and they are things that are then needed to follow through with that and for them it doesn’t tie in with what they wish for the end of life period but they’ve been able to make that decisions themselves so it’s right for them and their family and their child. There are certain time lines. (05HCP)* |
| Importance of raising the topic of organ donation |  |  |
|  | Giving parents the opportunity | *Even if they cannot donate organs or tissues I think we should ask but I think we don’t really give them the opportunity. (05HCP)* |
|  | Being asked is meaningful | *Some families where actually they declined the suggestion….but actually felt that being asked was a validation of their child and they found it very helpful. They were grateful that they were asked and it was meaningful to even be asked. (05HCP)* |
|  | Importance of choice | *And they have had that choice and I guess that is how I try and present it. it is a choice and if they don’t want it they don't have to go there but this a choice other people might want to have and we can’t not ask them because that would take that choice away from them. (05HCP)* |
| Assumptions from parents |  | *Often it’s ‘oh I guess our child can’t because they have a malignancy’ where actually often you can donate tissues, corneas, but I think families and professionals will just assume that they can’t. (05HCP)* |