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Editorial Article

How do you know what you know?
Recognizing practical knowledge in nursing

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A narrative of skilful nursing

Maria, a junior nurse, calls out to Julia her senior colleague to help her with her patient. Billy is a 14-month-old infant that underwent a minor surgical procedure 3 days ago. He had an uneventful post-operative course, but has been crying today for several hours. Maria is holding him, has tried to feed him and soothe him – but he appears completely inconsolable. Maria is desperate for some help.

Julia enters the room, examines Billy in a glimpse and holds her arms out for him. Within a few seconds, Billy stops crying. Maria noted that her senior colleague rocked Billy and captivated his attention: he seemed fully focused on her face and her voice. Julia adopted a particularly warm facial expression and tone of voice – quite different from the way she spoke with adults, while caressing his body. Finally, she turned to Maria and told her to page the physician on call, because she felt he might be "getting septic". How did Julia so effectively assess Billy's needs and comfort him so readily, while also assessing a possible underlying physiological problem?

What kind of knowledge is nursing knowledge?

A significant body of literature has examined questions regarding nursing knowledge: What kind of knowledge is this? How is it acquired? This paper reviews these questions. Although this discussion is relevant for pediatric intensive care nursing, it is addressed more broadly to nursing in general.

Several nursing studies have demonstrated the impact of nursing care on the psychosocial experience of patients and their families. Emerging research is illustrating that nursing can also favorably affect physiological types of patient outcomes such as mortality or morbidity rates.

Cho and associates (2003) examined the impact of nursing staffing levels on complication rates among more than 120,000 patients in 232 California hospitals. They reported that a one-hour decrease in daily patient care was associated with a 9% increased rate of nosocomial pneumonia and prolonged hospitalization.

Aiken and colleagues (2002) reported a relationship between nursing staffing levels and complication and mortality rates among more than 230,000 patients throughout the Unites States. The addition of each single patient to a nurse's workload was associated with a 7% increased rate of patient mortality and 7% increased rate of fatal complications.

It is quite clear that nursing care has an important impact on patient outcomes. The opening narrative in this paper suggests that it is not only the *number* of nurses that affects patient outcomes, but also the *quality* of the nurses' expertise. How can we distinguish greater from lesser forms of nursing expertise? Is this merely reflected by one's years of experience? How does experience relate to the acquisition of expertise?

Over the recent decades, nursing has systematically recognized scientific methods and research findings to strengthen the knowledge base of the discipline. Nursing has sought, with reason, to ensure its interventions are based on scientific evidence. Several nursing practices (e.g., excessive infection control measures) have been modified accordingly. Indeed the adoption of the scientific model in nursing has been enormously beneficial.

However, it is important to guard against the dismissal of other significant forms of nursing knowledge – to ensure that scientific validation does not become the sole standard for ascertaining nursing knowledge. In fact, practice disciplines, such as nursing and medicine, also rely on *practical knowledge* (PK) (Benner et al., 1999; Gordon, 1988).

Understanding practical knowledge

PK relates to what is sometimes called “savoir faire” or “know how”. This refers to a different form of knowledge – one that is sometimes vague, difficult to evaluate and teach, yet a vital type of knowing. For the purposes of this paper, PK includes a variety of terms such as tacit knowledge, practical wisdom, personal knowledge, reflective practice, and intuition, which will not be differentiated because of space limiatations.

Many trace the recognition of PK to the 1960s work of Michael Polanyi (1958; 1966). He described the tacit dimension of human knowledge in everyday life as well as in research laboratories. This relates to knowledge that cannot be explained theoretically, scientifically measured or verified, and commonly cannot even be verbally articulated. Examples can be seen in the ways a skilled musician can reliably reproduce specific sounds, that an athlete can perform extraordinary tasks, a skilled nurse that can always find a vein for an intravenous infusion (when no one else can), or a surgeon can consistently achieve pre-specified outcomes with highly variable patient body structures.

Our center was confronted with the complexity of PK in the early 1990s in a research study where we attempted to create an online vital signs evaluation system (Kairouz, Lam, Malowany, Carnevale, & Gottesman, 1994). Among other things, we tried to “teach” the computer how to monitor fluctuations in heart rate. A team of pediatric critical care nurses and physicians spent several days trying to explain to a group of engineers what constitutes a clinically significant increase or decrease in heart rate. Was it based on an absolute change in number? Or a percentage change? Or a change sustained over a particular period of time? Or a change associated with certain fluctuations of other hemodynamic parameters? We created various formulae, based on cardiovascular physiology theory, but the outcomes of the computer’s interpretations were inconsistent with what the experts judged as clinically important. It became apparent that the form of judgment that a skilled clinician can make in seconds with the glimpse of an eye, involved an order of complexity that was not readily explicable.

This is consistent with the findings of Patricia Benner (1984; 1999) and Bishop and Scudder (1990) through their analyses of nursing expertise, and Donald Schon’s (1983;1987) concept of reflective practice and “on-the-spot” experiments. Whereas a novice typically relies on algorithmic rules or “textbook” knowledge to deal with clinical problems, an expert draws on prior experience with hundreds or thousands of prior cases to readily discern what is clinically meaningful and judge the probable problem and effective course of action.

The skilful clinician can improvise in the face of novel or unfamiliar clinical situations, generate hypotheses while acting, and interpret the outcomes of action in light of the original hypotheses. This distinction (between higher and lesser skilled clinicians) was also evident in a study of diagnostic reasoning among a group of pediatric critical care physicians (Rashotte and Carnevale, 2004).

In other words, PK is not a form of nursing knowledge that is inferior to scientific knowledge. Rather, PK is complex and frequently (if not usually) the most reliable form of expertise that can be brought to bear in the management of clinical problems, because we do not have definitive scientific explanations for how to manage many clinical problems.

Recommendations for "practical knowledge based practice"

It is important to recognize the sophistication of skilled "know how" and the ways in which nursing expertise may be invisibly operating in the prevention of complications and adaptation of treatment plans for highly unique patients – partly explaining the improved patient outcomes associated with nursing staffing levels.

Recognizing PK poses the challenge of specifying how it can be fostered in order to ensure effective nursing practice. I recommend the following such strategies as a starting point, drawing on the various articles cited in this paper. This list is not by any means exhaustive:

1. Current initiatives to promote evidence-based practice should be complemented by the recognition and promotion of PK;

2. Nursing education programs should be structured in a manner that promotes the forms of reasoning associated with reflective practice (Rashotte and Carnevale, 2004; Schon, 1983;1987);

3. The process of adaptation by a novice nurse into a new clinical setting involves a prolonged period of time, optimally through mentorship programs where the novice is able to learn from a "master" as an apprentice;

4. The retention of expert nurses should be maximized, recognizing the complexity of nursing expertise that they bring to a setting; and

5. Nursing assignments and workloads need to be carefully examined to ensure that nurses' expertise corresponds with the complexity of patient needs and the overall needs of the unit (e.g., supervision of junior staff, monitoring for system failures).

Nursing services need to be structured and supported in a manner where cases such as the tearful Billy and his junior nurse Maria can always rely on the immediate availability of expert nurses with strong practical knowledge - like Julia.

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Information For Authors

Pediatric Intensive Care Nursing welcomes paper submissions for upcoming issues of this publication. Papers may focus on any clinical or professional topic relevant to nursing the critically ill child and pertinent to an international nursing readership. Submissions should be 3-5 double-spaced pages in length.

Send your proposed papers directly to Franco Carnevale (Editor):
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Truth and Consequences:
Parental Perspectives on Autopsy after the Death of a Child

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Abstract

Objectives: Autopsy is an important part of pediatric end of life care. Autopsies can provide concrete information about the pathology of a child's disease process, confirming or disconfirming ideas of disease mechanisms, diagnoses, and iatrogenic complications. This information can both further scientific knowledge as well as assist a family's grieving. This report explores parental experiences of the autopsy process after pediatric death in the Intensive Care Unit (ICU).
Methods: Twelve parents whose child died in the ICU of a tertiary care pediatric hospital were interviewed to understand their experience of the death. Investigators reviewed transcripts and observational fieldnotes. Multidisciplinary team triangulation was used to corroborate themes using cross-case analysis.
Results: One salient finding from this study concerns parental experiences and understandings of autopsy. Parents reported a variety of practices concerning the autopsy consent process. These practices included: a) the treatment team not approaching parents about autopsy; b) the treatment team directly asking parents about autopsy; c) parents broaching the subject of autopsy themselves; and d) the treatment team discouraging parents from autopsy. Four themes emerged concerning parental experiences and understandings of autopsy: 1. Autopsy and the advancement of scientific knowledge; 2. Autopsy and the cause of death; 3. Balancing the search for truth with the invasive reality of autopsy; 4. The protracted waiting for the pathology report.
Conclusions: These findings suggest that from parental perspectives, autopsy consent practices are variable. Further, parents reported beliefs and practices around autopsy that are contrary to scientific evidence about the benefits of autopsy for pediatric end of life care and family bereavement. Future work is needed to look at staff perspectives to further our understandings of these findings.

Background

Autopsy is an important part of pediatric end of life care for many reasons. Autopsies can provide concrete information about the pathology of a child's disease process, confirming or disconfirming ideas of disease mechanisms, diagnoses, and iatrogenic complications. Such information contributes to public health and medical practice. Further, this information can help to reassure an individual family about the care their child received, as well as about their decisions along the disease trajectory.[1-3] In so doing, an autopsy can assist a family's bereavement by increasing their understanding of their child's death and future pregnancy risks, while also providing the family the opportunity to contribute to science and thereby also help other families.[1, 3-5]

Despite the importance and benefit of autopsy, rates vary considerably and are reported to be declining.[3, 5, 6] While there are many socio-cultural reasons for a family to refuse an autopsy, the most common reason for not obtaining an autopsy may simply be the failure of the medical team to request one.[2] Further, while timely autopsy reports may promote closure and the processing of grief, pathology reports are often delayed, arriving weeks or even months after the death; the waiting itself can increase distress in families.[4, 7]

This paper reports on findings concerning parental perspectives on autopsy taken from the first phase of an ethnographic study to better understand the experiences of families confronted by the life-threatening illness of a child. The goal of this phase of the study was to better understand the experiences of parents whose child died in the pediatric intensive care unit (PICU) of a tertiary care university teaching pediatric hospital. As part of this study, parents were asked directly about autopsy, and this paper presents their responses. Other findings from this study have been published previously[8] and future publications are planned.

Methodology

Semi-structured interviews and field observations were conducted with 12 bereaved parents whose child died in the PICU of a 160 bed free standing pediatric hospital. This hospital serves a multicultural and multilingual population, and is one of two pediatric hospitals in a city of approximately 3 million. The 12-bed PICU is a cardiac and trauma referral center, has approximately 500 admissions per year, a mortality rate of approximately 7%, and an average length of stay of 6 days.

The human subject protocol for this project was approved by the hospital's Institutional Review Board. Participation was voluntary and written informed consent was obtained from all participants. Mortality statistics for the PICU were reviewed, from which a 15 month sample (April 2001–June 2002 inclusive) provided 20 families eligible for inclusion (2 families were ineligible for legal reasons). This time period allowed us to seek families who had a child die in the PICU between 9–18 months prior to recruitment, a period of time that provides distance from the death yet is not too remote as to affect ability to recall. Eight families agreed to participate and twelve parents were interviewed (8 mothers and 4 fathers) in English (n=7) and French (n=5). All parents were part of two-parent families, and many had multicultural backgrounds (e.g., Greek, Italian, Egyptian, Caribbean). The only reason stated for declining participation from parents was that they did not want to talk about the death. The deceased children were 50% female, their age ranged from newborn to 20 years, and their diagnoses included trauma, chronic and critical illnesses (a table with the description of the deceased children has been published elsewhere[8]). The majority of interviews were conducted in family homes; two parents chose to return to the hospital for the interview. Two parents were interviewed together, the remainder were interviewed individually. The first author, together with a research assistant, conducted all interviews.

A multidisciplinary research team reviewed all data (interviews and observational fieldnotes) from which they identified and corroborated emerging themes. An analytic framework of constant comparison analysis was used, beginning with case-by-case analysis (an interview was considered a "case") followed by cross-case analysis.[9, 10] Bias was minimized through data, method and investigator triangulation: two interviewers attended each interview (ensuring "double listening"[11]); two data sets (fieldnotes and interview data) were developed; a multidisciplinary team reviewed data and the interpretation of the data was reached with team consensus, thereby guarding against idiosyncratic interpretations of data. (More detail about recruitment, the interview guide, analysis, and rigour has been published elsewhere.[8])

Findings

Several salient themes emerged from this data directly concerning autopsy. As in many PICUs in North America, official protocol at this hospital is to request autopsy for every death. Table One summarizes parental recollections of the autopsy consent process.

Parental recollections of the autopsy consent process

Autopsy not discussed

In all but one family, parents remembered the topic of autopsy being brought up after the child died. Only one of the twelve parents said that the subject of autopsy was not raised. This mother explained this omission as being because the cause of death was clear and thus the autopsy was not necessary.

> *Mother: Why do an autopsy?… His heart was racing (chuckling). When the heart is going 300 beats a minute, I don't think they have much… No they didn't do an autopsy.*
> *Interviewer: And, they didn't even bring it up?*
> *Mother: No.*

Refusal

Of the remaining 11 parents, four parents said they were directly asked about autopsy and they all refused. Reasons for their refusal included one mother who said "*I don't think that I needed someone tell me what he died of,"* and a father who said: "*No we didn't want one. They had cut her enough, so we said no. She'd been cut everywhere.*"

Consent

Only two parents consented to an autopsy. One mother stated that she was asked directly and consented immediately. Another mother said that she did not remember exactly how the process happened but implied that she may have requested the autopsy herself:

> *Interviewer: Did they ask you if you wanted the autopsy or did they suggest it was a good idea?*
> *Mother: I don't remember how it happened, but I remember saying I wanted one to be done. So probably they don't do it all the… I don't know if they do it all the time. But I remember saying "I want to know, I want to know what happened for real…"*

Both these mothers were clear that their consent was directly linked to their desire for information on future pregnancy risks.

Topic broached but no formal request

The five remaining parents indicated that the topic of autopsy was broached, however they told us that a direct request was never made. Instead, the subject was presented by the treatment team as if a forgone conclusion: your child's death does not warrant an autopsy. The parents' understandings of this approach were the following:

a. The cause of death was clear

Two parents interviewed together said that the topic of autopsy was raised; however the attending physician discouraged them because the cause of death was clear:

> *Interviewer: Did you have an autopsy done?*
> *Mother: No.*
> *Father: No, we didn't. We probably should have but…*
> *Mother: The doctor had come in to us and told us that they would be*

> *coming in and asking us if we wanted an autopsy…*
> *Father: He recommended not.*
> *Mother: And he said, he recommended that we not have one, he said "[The baby] has been opened up enough. We basically know, we know what caused it, we know…"*

b. Autopsies are only for suspicious deaths

Similarly, according to the following mother, the doctor justified not needing an autopsy because the reason for death was clear. For the mother, this reasoning made sense because she felt that autopsies were only for "suspicious deaths:"

> *Mother: The morning she died, I think the doctor said "There won't be an autopsy because we know the reason for her death" And that was fine. It was the hospital that made the decision that there wouldn't be one. They said: "You don't need an autopsy, we know what happened"… For me, an autopsy is only for suspicious deaths.*

c. An autopsy would bring no further information

In the next example, the parents disagreed on exactly how the subject of autopsy was broached but agreed that the treatment team felt an autopsy was not warranted given that it would bring no new information to the case. The first interview quoted below is with the mother, however the father was in the room at the time the question came up and adds his opinion. In the second interview, weeks later with the father, the mother was in the room and added her opinion. In both cases, the mother stated that she was the one to bring up the subject of autopsy and was dismissed:

> *Interviewer: Did they ask you about autopsy?*
> *Mother: No.*
> *Father: Yes.*
> *Mother: No.*
> *Father: They asked us if we wanted one.*
> *Mother: Me, I asked the doctor: "Will you do an autopsy?" And she said: "Oh no, no."*

While the father believes that, technically, they were given the option to have an autopsy, he agrees that they were discouraged from having one. He feels the doctor implied that it would not bring new information to the cause of death, and therefore was not necessary:

> *Father: No, we didn't choose to have an autopsy.*
> *Interviewer: Why did you choose to not have one?*
> *Mother: Really, we didn't have the choice.*
> *Father: Yes, we did have the choice.*
> *Mother: Me, I felt we didn't have the choice.*
> *Father: We could have had one.*
> *Mother: I asked the doctor myself about an autopsy and she said: "No, oh no, an autopsy is not necessary."*
> *Father: The physician said to us (rhetorically): "What more would it bring you?"*

Themes

Overall, the interviews with these parents revealed four main themes concerning their understanding of, and experience with, the autopsy process.

Autopsy and the advancement of scientific knowledge

The issue of helping science by consenting to an autopsy came up in two interviews. For one mother, having the treatment team cite the advancement of science and the possibility of helping other families as a reason to justify an autopsy encouraged her to consent. In contrast, for one father, the knowledge that an autopsy might provide to advance science was "interesting" yet still was not worth the process of cutting into the body of his deceased child:

> *Father: I felt that she had suffered enough. She had needles everywhere, she'd been opened…. She'd been butchered enough. While I wanted to know the real cause of death, what would it really change? Maybe it could be good for others to know about real risk and what to pay attention to; at that level, it would be interesting. But in my life, that wouldn't really change anything, because it wouldn't bring her back.*

Autopsy and the cause of death

Most parents believed that the goal of autopsy was to determine the cause of death of the deceased child. This appeared in the interviews from two perspectives: a) the desire of the treatment team for information; and b) the desire of the parents for information. One mother said that the treatment team asked her if she "needed" an autopsy. She declined because she felt she did not "need" more information about the illness and cause of death. In contrast, the child's father stated that it was really the treatment team that wanted the information from the autopsy:

> *Father: They asked us to have one done. We refused.*
> *Interviewer: At that point, why?*
> *Father: What for?*
> *Interviewer: You knew [why he died]? [pause] Why would they want one, do you think?*
> *Father: Because they probably didn't know what he was – what his problem was.*

While this father was not certain himself about the exact cause of his child's death, he refused the autopsy because he did not believe that it would bring clarity. This was not because he felt the cause of death would not be uncovered by an autopsy, however. It was because he believed the health care system was corrupt and that the truth would be kept from the parents:

> *Father: You know, let's say they [the treating doctor] made a mistake or something, you know? You think they're going to come and tell the dad that, you know, that "We made a mistake?" No.*

While this may be an extreme example, other parents voiced their suspicions about the autopsy process. In each scenario in which parents were actively discouraged from having an autopsy, the parents were regretful that they had not pushed to have one, notwithstanding the advice of the treatment team.

One mother voiced her concerns about the consent process. She felt the hospital had made the decision not to do an autopsy without consulting her. She was told it was simply not necessary because the cause of death was clear. While generally confident in the opinion of health care professionals, this mother also had her doubts about the information given about her child's illness and death. In retrospect, this mother now wonders if perhaps a better model regarding consent for autopsies could be built. She suggested that a neutral person should be assigned to ask the parents about the possibility of an autopsy:

> *Mother: There should be someone from outside that comes and asks parents: "Do you have any doubts about the cause of death? Do you think the treatment that your child received caused your child to die?"*

Another mother also had regrets, and had suggestions about making the process more parent-friendly. She felt that she and her husband were expected to make a decision without the time or support to think through the pros and cons. Both she and her husband regretted that they took the advice of the doctor so quickly and refused the autopsy.

> *Mother: So I don't know, you know we have doubts, again, about that, so I think maybe… more counselling around that, eh? I mean, that's something that you have to make a quick decision with. I don't think it's something that really… you shouldn't make a quick decision about.*

> *Father: Yeah.*
> *Mother: Yeah. Or even let them know the next morning or…*
> *Father: Yeah, yeah. Well [the doctor] recommended not having it done.*
> *Mother: Yeah, yeah.*

Balancing the search for truth with the invasive reality of autopsy

While autopsies are understood as the last chance to discover information from the body about the child's illness and death, some parents were conflicted about this search for truth given the bodily mutilation required by the autopsy. Some parents were aware that the autopsy had intrinsic limits and might not provide them with clarity concerning the cause of death. This, plus the invasive reality of the autopsy, made it hard for some to justify this search for truth. The possibility of the autopsy bringing some clarity is attractive for the following mother:

> *Mother: But I think, afterwards, having questions, wondering that maybe we should have had one done… Maybe that would have given us the answers. I think that was a question that we brought up though, and the doctors told us, they said it would not have given us the answers. It's something though that I still think: "Oh I would have liked to know for sure." 'Cause if that would have given us the answers, it would have been nice to have known.*

However, she then goes on to say:

> *Mother: And then, I think another part of me thinks: "I don't know if I could have handled [the baby] being cut up again," you know? You know, it's not a wonderful thing… Although I guess this time he wouldn't have felt it. I guess it's more invasive for us thinking about it…*

While this mother added: "*I guess this time he wouldn't have felt it,*" this gave her little solace. According to this mother, even physicians were uneasy with the invasive aspect of autopsy:

> *Mother: And [the doctor] said, he recommended that we not have one. He said: "[The baby] has been opened up enough. We basically know, we know what caused it, we know…"*

One might assume a parent's concern about the bodily mutilation required by an autopsy could be related to the number of invasive procedures their child's body had already undergone. While this does not seem to be the case in our study, our sample is too small to say anything conclusive about this. Interestingly, however, the two parents who agreed to an autopsy did not mention bodily mutilation in their interviews, despite their children both experiencing major surgery. The autopsy itself was a minor detail in their interviews; instead, as will be discussed below, common to their stories was their intent on continuing to raise a family and the related frustration at the lengthy pathology reporting process.

Protracted waiting for the pathology report

For the two parents who did consent to autopsy, a large concern for both was the lengthy pathology reporting process. For one mother, her sense of urgency to get the pathology report was directly related to her own declining fertility:

> *Mother: And you know, I have… I'm 37 years old and I was checked in fertility before I got pregnant and the doctor said "You're fine, but your months are counted", because all the women in my family are menopaused… at 40 everything's over. So at 38, 39 you start skipping periods and stuff like that so you're not very fertile at that point. So the doctor told me "If you want to have kids, it's now. Don't wait 2 years; in 2 years you won't... you probably won't be fertile anymore." And he told me "Wait 6 months, after you can start trying".*

Yet, by 6 months the results were still not in. The couple went ahead and conceived, their logic being the following:

> *Mother: And by 6 months we thought the pathology results would be in so we would know if it was a genetic problem or not. Six months after the death, I got pregnant again. But we thought we're gonna have an amnio done on the 16th week, so we thought at the 16th week, the pathology results will be in, we'll know if it's genetic or not and if it is, the amnio will tell us if there's a problem with this one or not. And at the 19th week we'll see by the ultrasounds. So with all the experience that we've been through, I think I can make a clear decision at week 19 to stop the pregnancy or not. It's cruel, it's really tough, but you have to go through that if you wanna have children, you know.*

By the 19th week, the report was still not in. She tried calling the lab, to no avail:

> *Mother: And when I called, it was like if I would call for the weather report, you know? It was really cold like: "We do have a lot of work and it's not ready."*

The scenario for the second mother was similar: She was keen to have another child, however was worried about what the pathology report might say about genetic problems. While she was very concerned about the report, no one at the hospital seemed to share her worries. This was partly reassuring for her, but partly disconcerting:

> *Mother: I think the [doctor] had told us that they hadn't found anything with [the baby], like aside from his heart, that they had tested but she wasn't sure. Actually that was the only thing that was kind of like… that we never got an answer on. She said she* thought *that they had tested him but the lab was closed [so she could not check]. So that, we never got information on. But I was assuming if they had found something that they would call me back, 'cause it would be nice to know for future pregnancies. But I sort of said, you know what, like she said: "I'm pretty sure they didn't find anything," and I sort of went on that. I asked a couple of times to see if the results had come in, but… I asked, I called [the nurse] to see. I remember, like: "Did the results come in?" And then it took quite a while, but in the end we didn't really get the official results.*

Both these mothers believed that that autopsy report would help them make decisions about future pregnancies, yet neither received the information before getting pregnant. Fortunately, in both cases, their pregnancies proceeded safely and they delivered healthy children.

Continued on next page.

Table One: Parental recollections of the autopsy consent process

Family # **n=8 families** **n=12 parents**	**No mention**	**Mention by Dr**	**Mention by Parent**	**Request by Dr**	**Consent**	**Parental reasoning**
1:Mother		✓		No		Cause of death clear Cause of death not "suspicious"
2:Mother			✓	No	No	Would not bring new information Excessive cutting of the body
Father		✓				
3:Mother Father		✓		Yes	No	Cause of death clear
4:Mother Father		✓		Yes	No	Excessive cutting of the body
5:Mother		(does not remember)		Yes	Yes	Future pregnancy risk To find "real" cause of death
6:Mother Father		✓		No		Cause of death clear Excessive cutting of the body
7:Mother	✓					Cause of death clear
8:Mother		✓		Yes	Yes	Future pregnancy risk Helping science

Discussion

As in many PICUs in North America, official protocol at this hospital is to request autopsy for every death; autopsy can provide clear benefit to both science and family bereavement. Contrary to this protocol, one family in our study did not remember being asked about autopsy, and of those for whom the topic was broached – sometimes by parents themselves – many felt that they were not actually "asked" to consent. Instead, many parents felt the decision to have an autopsy remained with the treating team and they were discouraged from pursuing an autopsy. Only two of the eight families consented, and their consent was directly tied to their future pregnancy risk.

At the time of the death of a child, making a clear, informed decision about autopsy may be difficult for parents given the intensity of their grief, fatigue and sadness. Further, this decision is irreversible, adding pressure to the process. Having a trusted health care professional guide this decision may be comforting for parents and this may help explain why many parents felt that the decision lay with the treatment team and why parents did not, originally, contest this. What is disconcerting, however, are the regrets and suspicions some parents were feeling months after the death concerning this autopsy process.

Regardless of their emotional state at the time of the death, parents have the right to know what the autopsy can bring to them, and the irreversibility of their decision. The suggestion that an autopsy would not bring new information is contrary to research evidence that shows the ability of autopsy to expose new or additional information[3, 12] Further, the connection of autopsy with suspicious deaths probably reflects the parent's confusion between a coroner's report and autopsy. With supportive counseling, a parent's decision to consent or refuse an autopsy would be informed and truly their own, and would hopefully reduce misinformation, suspicions and regrets.

A parent does not necessarily separate the living or spiritual essence of their child from the body on the pathologist's table. Some parents saw the autopsy as a procedure that would bring self-interested knowledge to calm their own desire for answers, and they had to weigh this desire against the fact that autopsy would: a) not help their child; b) not bring the child back to life; and c) involve further mutilation to the body. Altruistically helping science or helping other families was not a strong motivator for them, contrary to the suggestion of other studies.[1, 3-5] Parental concern about the invasive reality of autopsy and the mutilation of the body has been found to be the most common reason for not consenting to autopsy.[3, 5] These issues are relevant to other areas of medicine such as organ donation[13, 14] and this is obviously an area for future study and clinical intervention.

When a child is critically ill, medical tests and procedures are often done with great immediacy. After the death, urgency wanes; at least, this is how two parents experienced waiting for the pathology report. This study backs up other studies that suggest that the protracted waiting can actually increase a parent's distress.[4, 7] Further, our study shows that the waiting can complicate parents' decisions to have more children.

It is important to remember that our data is based upon parental recall. Our study was not a fact-finding mission regarding autopsies; instead, the data represents parents' memories of the autopsy process. We do not know if these parents were asked about autopsy; we simply know that many do not remember being directly asked to consent, and some felt they were actively discouraged from consenting. Similarly, we do not know the motivations behind how the treating team approached the topic with these parents. Given that this data implies that there may be considerable variation in staff beliefs and practices around autopsy, areas for future study include examining such things as: staff beliefs and understandings of, as well as attitudes towards, autopsy; how autopsy discussions are framed; and staff education regarding autopsy practices and protocols.

While there are limitations to the data, important take-home messages remain. Regardless of what "objectively" may have unfolded in the PICU, it is important to hear what the parents are saying about beliefs and practices around autopsy and pathology reports. Regardless of what "really" happened, these are their memories of the events and thus are "real" to their experiences as they live with the memories of the death of their child.

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Spotlight on PICU

This regular column will provide readers with an opportunity to learn about fellow PICUs in various parts of the world.

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Pediatric Intensive Care in Melbourne, Australia

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The Royal Children's Hospital in Melbourne was established in 1870 and is a 250-bedded specialist pediatric hospital, providing a full range of clinical services, tertiary care and health promotion and prevention programs for children and adolescents. The hospital provides specialist pediatric care for children within Victoria, but also cares for children from Tasmania, from the other Australian states and territories and from overseas. Approximately 32,000 inpatients are treated each year while 280,000 children attend the hospital on an annual basis.

As a leading pediatric teaching centre the hospital has affiliations to the University of Melbourne, La Trobe University and other universities providing postgraduate studies. The Murdoch Childrens Research Institute based at the Royal Children's Hospital provides the capacity to undertake "bench-to-bedside" research.

The Pediatric Intensive Care Unit (PICU) currently has 15 beds, with the capacity to open to 24 beds, and cares for children from 0-16 years of age. The unit provides care for children with medical, surgical and cardiac conditions, and is the Pediatric Heart Transplant Centre for Australia. In 2005, 1422 children were admitted to the unit with an average length of stay of 4 days.

The care of each PICU patient is managed by the PICU consultant on duty, with a team of PICU registrars and fellows, and also by a non-PICU consultant with their team. Other specialist services are consulted as required.

Over 100 nursing staff work within the unit, with many possessing postgraduate qualifications in pediatric intensive care. The Post Graduate Diploma in Advanced Clinical Nursing (Pediatric Critical Care) is conducted from within the ICU in conjunction with the University of Melbourne. Apart from the Nurse Unit Manager there are 10 Associate Unit Managers, numerous Clinical Nurse Specialists, and Registered Nurses. Clinical Nurse Educators and Clinical Nurse Facilitators support students and staff within the unit. Education is provided by regular workshops, study days and outreach programs to nursing colleagues from within and outside of the unit.

A Pediatric Emergency Transport Service (PETS) is run from within the PICU and provides 24-hour emergency referral and transport for sick children from within Victoria and occasionally interstate. Approximately 600 patients per year are referred to the service with 300-350 being admitted to the hospital. The program is managed by a Nurse Coordinator. Senior nursing staff qualified in all aspects of patient retrieval provide 24-hour support along with medical colleagues.

The Extra Corporeal Life Support (ECLS) program commenced at the hospital in 1985 and to date over 400 children have been supported with Extra Corporeal Membrane Oxygenation (ECMO), and Ventricular Assist (VAD). The last 12 months has seen 3 children supported with the Thoratec, with subsequent heart transplantation. A Nurse Coordinator, a Medical Coordinator and 2 other Intensive Care consultants manage the program. Support is also provided by perfusion services. There are approximately 20 ECLS trained nurses who provide 24-hour cover.

A yearly ECLS course is run from the unit with nursing and medical personnel attending from within the unit, interstate and overseas. The course content is based on the requirements stipulated by the Extra Corporeal Life Support Organization. Regular meetings, workshops and study days are provided.

PICU liaison nurses provide staff support within the unit and to colleagues on the wards. Their role is to provide support, follow up and advice on all patients discharged from the unit. Education is also provided to unit and ward staff, with ongoing support to the wards accepting patients from PICU. The ultimate aim is to decrease the potential for readmission to the unit.

Four Intensive Care Technologists provide a support service to the unit, the wards and occasionally the Royal Women's Hospital which is nearby. They offer assistance and support with PETS, ECLS and ventilatory and filtration modalities. The technologists also provide maintenance and education on the different equipment used within the unit. They are also involved in research.

The unit could not function without our support staff including ward clerks and patient services assistants.

Please feel free to visit our website at www.rch.org.au/PICU for more information.

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