PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #400
DISCUSSING AUTOPSY WITH BEREAVED FAMILIES
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Background Autopsy remains an important quality measure, serving to advance disease understanding, identify diagnostic errors, educate trainees, and provide information about causes of death (1-6). Yet, autopsy rates have declined worldwide (3,5,7). Clinician hesitancy to seek consent from bereaved family members is a contributing factor (5,7), as is a perceived lack of clinical training in the autopsy consent process (5,6,8). This *Fast Fact* addresses best practices in discussing autopsy with decedents' families. We restrict our discussion to non-forensic hospital autopsies (8,9).

Family Considerations Despite clinician fears about upsetting grieving families, evidence from small studies suggest that often families are willing to consent for autopsy when counseled appropriately (10,11). At a few institutions, offering an autopsy is the norm. Most families are never asked, however (5,11,12), and those who are report that hurried, insensitive conversations contributed to their emotional distress (13,14). There are several potential benefits for bereaved family members. The most extensive research available is on perinatal loss. Amongst parents who experienced a neonatal death, autopsy helped explain what happened, facilitated future family planning, addressed their altruistic desire to prevent stillbirth in others, and aided in the grief process by supporting a sense of emotional "closure" (13-15). Common reported reasons for families declining autopsy include concerns about bodily integrity and dignity ("she's been through enough already"), stress of giving permission, objections from other family members, misunderstanding about why autopsy is being requested, religious and cultural objections, and concerns about interference with funeral arrangements (6,8,16).

Best Practices Recommendations in the table below are based on reported family and clinician perspectives, expert opinion, and general serious illness communication techniques. Ideally, consent should be obtained by an experienced and familiar clinician (17,18). Clinicians should understand the administrative logistics of their practice setting, such as whether their hospital covers the autopsy cost.

Steps	Example language
1. Begin with introductions and an expression of empathy (9). Use the deceased person's name (18). Avoid words like "corpse" or "cadaver."	*[Introduce yourself.] I'm so sorry for your loss. My condolences to you and your family.*
2. Introduce the concept of autopsy and acknowledge the sensitive nature of the discussion.	*I'd like to talk to you about an autopsy, which can have several benefits for grieving families. I know this can be difficult to think about.*
3. Elicit the family's reaction and find out what they would like to know (18-22).	*What are your thoughts when I mention an autopsy? What would be helpful to know?*
4. Explain why the request is being made (8,17,23). For perinatal deaths, avoid referring to future pregnancies during this conversation (13,18).	*This exam may…* *-Provide useful information and feedback to the clinicians about their diagnosis and treatments.* *-Assist in the grieving process, as some find comfort knowing more about the cause of death.*
5. Explain what happens during an autopsy, who/what/when/where, type/scope, removal and retention of organs/tissue, special tests (especially if they could cause delays) (9,22,23). Use understandable terminology and avoid graphic details. The College of American Pathologists has a handout for families on autopsies that answers common questions (23): https://documents.cap.org/documents/2017-autopsy-brochure.pdf	*An autopsy is an external and internal examination of the body performed after death using surgical techniques. The procedure occurs here and usually takes a few hours. It is done by a pathologist who is a medical doctor trained in this procedure. It can be comprehensive or limited to certain organs (although the latter can decrease what can be learned). Samples are collected in case microscopic examination, gene studies, or toxicology tests are necessary.*
6. Anticipate and address common concerns:	

Concerns about disfigurement: Clarify the professional nature of the procedure and reiterate that the body is not desecrated or mutilated (8,17,23). Clinicians may offer a limited autopsy, in which families can specify exam extent, including avoidance of certain body parts. **Note:** this is not true of medical examiner cases. **Impact on funeral services:** Discuss the family's desired timeframe and reassure them that exams are typically brief and should not interfere with arrangements. The patient's body may have external scars, but these will not be visible if the body is dressed for an open casket (8,17,23). **Costs to the family:** Typically, there are none, but check with your institution's practices.	*Autopsy is like a surgical procedure and is carried out by medical professionals who treat your loved one's body with care and respect. Outward appearance is not altered in a way that would be evident in an open casket. You can specify what you do and do not want examined, and the family's wishes are always followed.* *Exams typically take 2-4 hours to perform and should not interfere with funeral arrangements. Our staff are used to working with funeral directors to avoid delays to services or burial.* *Because this autopsy helps improves our care, there are no costs to you.*
7. Discuss a follow-up plan, including when/how/to whom results will be communicated. Prepare families for a potentially long wait time. If practical, arrange an in-person meeting (9,13).	*You'll receive a written report which is part of your loved one's medical record. Sometimes the results can take weeks to months to receive because of the detailed information gathered.*

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