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Original Publication Citation

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https://scholarsarchive.byu.edu/facpub/660

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AUTOPSY IN THE CANCER PATIENT
THE NURSE'S ROLE

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ABSTRACT

Nurses spend many hours with dying cancer patients, developing close relationships with both the patients and their families. However, nurses are frequently not involved in the process of requesting an autopsy, either by choice or tradition. During this time of great stress, the nurse can be more involved. The nurse who understands the reasons for autopsy and its ramification for the grieving process can be actively involved in supporting the physician who makes the request and the family members who must make the this difficult decision. It is possible that the nurse can be the health team member designated to actually make the request, thus adding a dimension of sensitivity to the death which may be difficult to achieve in traditional health care settings.
AUTOPSY IN THE CANCER PATIENT

THE NURSE'S ROLE

In the hospital, the extended care facility, and the home, nurses are involved in providing final care for the patient who has died and support to the patient's family or significant others. Nurses may find themselves present or in close proximity when consent for an autopsy is requested. What is the nurse's role at this critical time? Probably in no other situation is the physical and emotional expenditure on the part of the nurse more intense than with the patient dying of cancer. Often, the nurse has been involved in providing care to the patient for many days or months. It is the nurse who has built a relationship with the patient and family which has evolved into trust and possibly friendship. It is this relationship which allows the patient and family to ask questions and gather information. It would seem, then, that at the time of death and the request for an autopsy, when the family may be at its highest level of crisis, the nurse should be present and involved. Boers (1989) states,

"...it (the autopsy) is undoubtedly the last encounter between a physician and his or her patient; it is a natural endpoint of their relationship. As such, the autopsy should be a clinical procedure as normal as history taking and physical examination."

How true it is then that a request for autopsy should be an appropriate time for the nurse to at least be present. Perhaps it is the nurse, who has spent more time with the patient and the family than the physician, who should actually make the request.

In order to be truly supportive to the significant others of the cancer patient at the time of
Autopsy request, it is important to understand the reasons for doing the procedure. It is also important to be sensitive to the ramifications that such a procedure may have in the grieving process.

There are many good reasons for performing an autopsy. Establishing the cause of death is a primary reason. The Utah Medical Examiner Act of FY 1989 states,

"Autopsies shall be performed to aid the discovery and prosecution of crimes, to protect innocent persons accused of crime, to disclose hazards to public health by communicable disease, occupational diseases, or by dangerous drugs, chemicals or foods."

Nemetz (1987) lists the advantages of an autopsy in assisting with liability as follows:

1. Autopsies eliminate suspicion.
2. Autopsies provide reassurance to families. This author would add that this reassurance is that negligence did not exist on the part of either the family or the health care system.
3. Autopsies substitute facts for conjecture.
4. Autopsies construct a better defense.

Even though cancer patients are usually under medical care for a long period of time, the circumstances accompanying death may fall within those outlined above. With the current ability of people to be mobile in their life style, increasing crime rates, especially homicide, rising rates of abuse of the elderly, and given the fact that cancer patients are not immune to all the other entities of disease and trauma which effect mortals, it is certainly not unthinkable that a patient with cancer could die distantly from his primary care physician or from some condition other than cancer. One such instance helped to motivate this article. A patient under active therapy for his cancer was found dead in his home. His primary care physician could not attribute his death to his cancer or its treatment with certainty and the case was turned over to the medical examiner for a determination of the cause of death. When an autopsy is legally required, the situation may be
very traumatic for the significant others. In the authors situation, the family was very traumatized, nearly hysterical, and lacking any understanding of why the physician could not just sign the death certificate. The family may look to the nurse who has been working with them for months to help them find some sanity in the craziness of the situation. The nurse can be with them, attempt to explain the legalities of the situation and comfort them, explaining that the procedure will provide information about the true cause of death which may or may not have anything to do with the cancer.

Though establishing the cause of death is very important there are other reasons for performing an autopsy. Nemetz (1987) lists 13 reasons. Gloth and Burton are more concise.

"Autopsies serve basically two purposes:

Quality Assurance. They help to improve medical care and prevent the potential "burying" of mistakes without the analysis of prior medical care. In fact, studies have noted major diagnostic discrepancies between premortem assessment and necropsy findings. ...

Clarification or discovery of diseases, diagnoses, or untoward events. The information obtained from an autopsy is particularly useful to the clinician by providing answers to clinical enigmas and by allowing direct feedback on the presentation of various disease entities. Such an instructive mechanism is more potent, since it involves a scenario with which the primary care physician has been directly involved.

Information from the autopsy may alleviate family concerns or guilt, may resolve insurance of medicolegal controversies, may provide hereditary or contagious disease information, or may contribute to the attainment of accurate epidemiologic data. Indeed, unsuspected diagnoses found at autopsy provide valuable information on the occurrence rates of diseases.

If it is obvious why the patient died and there are no legal reasons for performing an autopsy, this should not be used as a reason for doing the procedure. To say to the family of a cancer patient who has suffered with the effects of a malignant disease for many months and
expired as a result of those effects, that the physician wants to establish the cause of death with an autopsy is incorrect. It is also confusing to the family. It conotates that even though the patient has been under treatment or care for the cancer for an extended period of time, the caregivers really did not understand the nature of the illness. It may be more correct to say that though the patient died of his cancer, an autopsy could help in understanding the actual process by which the cancer took the patient's life. If the cause of death is not in question, it may be better not to ask for an autopsy at all, or ask on the basis of another reason.

The reasons should be used appropriately. Soman (1987) stated in a letter to the editor in JAMA,

"...Residents are strongly encouraged by many attending physicians to obtain autopsies whenever possible. We have seen physicians mislead grieving families (telling them that an autopsy might help clarify the cause of death when this cause was known with near certainty) and intimidate families (with the idea that "it might be something genetic").

Despite having heard all of the logical and intellectually satisfying arguments about why autopsies are desirable, many physicians have difficulty justifying disfigurement of the recently deceased when there is no clear gain. ..." (above parenthesis by Soman.)

Soman touched on one of the ramifications for grieving, that of disfigurement. At the time of the request for an autopsy, the family or significant other may refuse the procedure saying, No, I don't want him to suffer anymore." Logically, this comment makes no sense, since the patient's body is in no state to feel anything. Perhaps the suffering being spoken of is the suffering of the family or significant other as they are frustrated in their attempt to make closure on the life of the patient and continue with the grief work necessary to resolve the grieving process. Even though the delay caused by an autopsy may be very short or none at all, it may still be more than the family can tolerate. The family may also feel quality at having allowed the patient's body to be handled or studied above and beyond what the patient tolerated during their life.
Another ramification of autopsy for the grieving process is the financial implications. The family of the deceased should be assured that there will be no cost to them for the actual autopsy from the institution performing the procedure. This unreimbursed cost to the health care institution is identified as one of the factors contributing to the current decline autopsy rates. (Webster, 1989) However, the family should be informed that an additional charge for preparation of the body at the funeral home may be incurred as a result of the autopsy. This charge is variable, depending on the state, the funeral home, and the extent of the procedure performed at autopsy.

Autopsy rates have declined from 50% in 1940 to about 15% in 1990 according to Gloth and Burton (1990). Writers list a number of reasons. (Nemetz 1987, Gloth and Burton 1990, Clayton and Sivak 1992) However, all of them list the requesting procedure as a problem. Biehn (1986) states,

"The task of requesting permission for a postmortem examination is usually delegated to a physician or nurse who involvement with the deceased has been peripheral at best. I have observed that medical students and junior physicians are often required to make such requests, without the benefit of support or observational experience. The inevitable uncertainty and discomfort may result in failure to obtain consent."

Webster (1989) states,

"Many younger physicians are unfamiliar with the process and methods of consent for an autopsy and therefore may never acquire this skill."

Gloth and Burton state, "The most discouraging reason for not obtaining a postmortem examination is that the request was never made." Clayton and Sivak state, "Reasons cited for the decline include ... the lack of an organized mechanism of requesting permission for autopsy."

Hershey (1992) says,

"Now we finally come to the request for autopsy. We have a resident in the early morning hours in between other pressing duties working with a family he/she does not know and possibly required to answer questions regarding diagnosis and management
concerning a patient he/she does not know. It is very difficult to expect this individual to have cogent arguments for the performance of an autopsy. It is also unreasonable to expect any physician, no matter how skilled, to establish trust and rapport in this brief emotionally strained period of time."

These writers allude to the idea that the discomfort and inexperience of physicians who request an autopsy may be a significant factor in the decrease of autopsy rates. More importantly, the physician’s difficulty in making this request at a time when family members or significant others are severely distressed serves only to increase the crisis level of the situation. It is unnecessarily painful to inflict such stress on the family members of a deceased cancer patient when they may have already been stressed to nearly impossible limits by the length of the dying process through which both their loved ones and themselves suffered. Training in interpersonal relationship skills and in the specifics of dealing with people at such stressful times, as at the death of a loved one, would decrease the discomfort of the person requesting the autopsy, decrease the distress of the patient's family and improve the quality of care at the time of death. Clayton and Sivak (1992) actually performed a study at New York Medical College to provide such needed training to physicians and found that their autopsy rates increased from 10% in 1990 to 27% in 1992.

It is important that nurses be active in the process of requesting an autopsy. The support of the nurse is important to the family at this critical time. The nurse who is present at the time of the death should make an effort to see that the person called to speak to the family is that person closest to the patient during his life. If another nurse was particularly close to the patient, she should be called. If a physician is required to request the autopsy, it should be the physician most familiar with the case. This may not be the physician who pronounced the patient dead. In institutions where an "on call" system is used, the person pronouncing the patient may be a
physician who has never seen the patient. A physician who does not know the patient cannot be as sensitive with the family or give them as much correct information as a physician familiar with the case.

Efforts should be made to provide a quiet place where the interaction of the care providers and the family can take place. This should be a place with sufficient chairs to accommodate all persons wishing to be at this meeting and which will facilitate a caring personal atmosphere. Distractions should be held to a minimum. The caregiver making the request should have someone take phone messages for him if necessary. However, this should not be the nurse who is specifically there to support the family. That nurse should be present solely for the comfort and support of both family and the care provider making the request. The meeting should take place as soon as possible, so that family can be free to carry out other plans as necessary.

The family should be informed about how and when the results of the autopsy will be available. Every effort should be made by the institution to provide these results in a timely fashion, hopefully within seven days. The results should be in a language the family can understand or be interpreted or clarified by someone they trust.

Another role that the nurse may take in obtaining consent for the autopsy is to actually be the member of the health care team to obtain the consent. McPhee (1986) noted that 25% of the families involved in his study were asked for consent for autopsy by nurses or social workers. The designation of physician as the member of the health care team to ask for consent may only be assumed instead of mandated by individual state law or hospital policy. A nurse in the role of the person to ask for autopsy consent would add another dimension to this difficult task. If the nurse were designated by a facility to provide this service as part of a designated job description, he or she may be able to spend more time with the patient and family
prior to the patient's death and more time of comfort and support with the family after the death. She would be able to prepare the patient himself for the question of autopsy. This is particularly true in cancer patients, since most cancer patients have many months to deal with their disease and prepare for their death. The cancer patient who is able to make the decision about autopsy for himself, in collaboration with his family, may relieve his loved ones of the weighty responsibility of making the decision after the patient dies. Louis V. Rosell, DO reports an unusual request from one of his patients who was suffering from a terminal disease. He quotes his patient and comments on her request:

"Doctor, I have my little girl to think of, as well as other patient who may be faced with this disease. I would like to sign my own autopsy permit.'

The emotional impact of her request prompted me to leave the room. The details were left to the nurse, who witnessed the final, unselfish gesture of this 39-year-old dying mother."

A nurse who has dealt with cancer patients over a long period of time may be more familiar with the patient's case than an "on call" physician who knows the patient only from the experience of pronouncing his death. Such a nurse would be more capable of providing comfort and support to the family than other staff who does not know the patient, who do not have time to spend with the family, or who are more uncomfortable with the death of the patient than the family themselves.

Though death may bring great relief for the cancer patient and his significant others, it can also be a time of great distress and crisis. It is hoped that in the future nurse will be willing and be allowed to take a more active role in obtaining autopsy consent. Requesting an autopsy is a very delicate and sensitive procedure and nursing has so much more to offer in this situation than they have been allowed to offer in the past.
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