A Staff Dialogue on Do Not Resuscitate Orders: Psychosocial Issues Faced by Patients, Their Families, and Caregivers

ELIZABETH M. O’SHEA, RICHARD T. PENSON, THEODORE A. STERN, JERRY YOUNGER, BRUCE A. CHABNER, THOMAS J. LYNCH, JR.

Hematology-Oncology Department, Massachusetts General Hospital Cancer Center, Boston, Massachusetts, USA

Key Words. Cancer · Resuscitate · Caregivers · Psychosocial · Palliative care

ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded The Kenneth B. Schwartz Center at MGH. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery which provides hope to the patient, support to caregivers, and encourages the healing process. The Center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members.

The following case of a woman who developed lymphoma was discussed at the July and August, 1997 Schwartz Center Rounds. There were considerable delays and uncertainties in the diagnosis, which was followed by an unpredictably chaotic clinical course. Although she had made it clear to her doctor that she did not want “heroic measures,” she had unexpectedly rallied so many times that her son and her husband wanted her doctors to do everything possible to keep her alive, including the performance of cardiopulmonary resuscitation (CPR). The clinical benefit of CPR in the event of cardiac arrest in those with cancer is discussed, as are do not resuscitate (DNR) orders, living wills, and healthcare proxies. In addition, the issues that surround DNR status, including who should discuss DNR status with a patient, and how and when it should be discussed, are reviewed. Staff raised concerns about the effect of discussing DNR status on the doctor-patient relationship, and wondered whether writing DNR orders adversely affect the care of patients. The Oncologist 1999;4:256-262

PRESENTATION OF CASE

Mrs. A., a 56-year-old woman, had been in good health until she presented with multiple episodes of fever. A diagnosis of viral illness was made and she was treated symptomatically. However, her daily fevers persisted for six months and because of peripheral neuropathy, she was confined to a wheelchair. When admitted to her local hospital, CT scans of her abdomen showed evidence of liver and kidney abnormalities. A bone marrow aspirate and biopsy were performed, and interpreted as normal. Two months later multiple nodules were detected on her chest x-ray. A fine needle aspirate of one of these was performed, which revealed an abundance of monomorphic glandular cells, suspicious for a low-grade adenocarcinoma; however, these sparse, highly atypical, degenerate lymphoid cells raised the possibility of a lymphoma with secondary, reactive, epithelial changes.

Correspondence: Bruce A. Chabner, M.D., Hematology-Oncology Department, Massachusetts General Hospital Cancer Center, Cox Building, Room 640, 100 Blossom Street, Boston, Massachusetts 02114-2617, USA. Telephone: 617-724-3200; Fax: 617-724-3166; e-mail: bchabner@partners.org Accepted for publication May 27, 1999. ©AlphaMed Press 1083-7159/99/$5.00/0
Mrs. A. was referred to a medical oncologist with a diagnosis of low-grade adenocarcinoma, consistent with a bronchoalveolar cell cancer. When first seen, she had herpes zoster, mucocutaneous candidiasis, splenomegaly, multiple pulmonary infiltrates, diffusely enlarged kidneys and extensive cystic changes in the liver. She was immunocompromised, with a low IgG level and a CD4+ count less than 50 mm. HIV testing was negative. Video-thoracoscopy with a biopsy was performed, and after considerable debate a final diagnosis of a high-grade diffuse large cell, T-cell peripheral lymphoma was made (although lymphoid granulomatosis could not be ruled out). With CHOP chemotherapy fevers defervesced and she felt significantly better. Following four cycles of chemotherapy, a CT scan revealed several new hepatic lesions. Eventually, a liver biopsy confirmed anaplastic large cell lymphoma. She commenced salvage treatment with ESHAP chemotherapy, and high-dose chemotherapy supported by peripheral blood stem cell reinfusion was planned. Her management became more complicated when she fractured an osteoporotic ankle and developed a neuropathic arthropathy; she also had multiple attempts at peripheral blood stem cell collections, urinary tract infections, neutropenic sepsis, and, finally, congestive heart failure. She was pancytopenic; a bone marrow biopsy showed extensive infiltration by lymphoma. The issue of proceeding with transplantation was moot; instead, a long discussion ensued about her poor prognosis. In an attempt to make her as comfortable as possible, she was started on prednisone. She responded dramatically; her fevers resolved and her blood counts improved.

During the next year she was treated with CVP chemotherapy, interferon, and a phase I agent; all resulted in little benefit. Again her health deteriorated; she developed severe mucositis and became bedridden. She was hospitalized with fever, dehydration, near-syncope, and severe esophagitis. During the entire hospitalization she was pancytopenic and required nutritional support. She received morphine for pain and was often confused. Complications also included pulmonary edema, hypotension, fungal sepsis, and renal failure. From the medical standpoint her situation was rapidly becoming irreversible, yet the family was not convinced that ongoing support was no longer indicated.

Prior to this diagnosis Mrs. A. had no significant medical history. She had been married for approximately 30 years; her husband, an attorney, had essentially given up his practice to care for her. As her primary caregiver he was devoted; he provided round-the-clock care, only occasionally assisted by a visiting nurse assistant. They had a 30-year-old unmarried son, who had been less involved in her care.

There appeared to be nothing further to offer her. Her husband seemed to agree that the medical team had done enough, but he would not challenge his son who felt strongly that not enough had been done. Medical staff believed that the son held unrealistic expectations, and that he challenged what was understood to be his mother’s pre-morbid wishes. From a medical point of view her care was futile; yet her son had essentially become her proxy. Several members of the medical care team, during repeated and in-depth discussions, were able to help the son develop realistic expectations, to understand what were felt to be the patient’s wishes, and the medical perspective of the natural history of her condition. He was able to accept do not resuscitate (DNR) status and comfort measures were provided. Her condition continued to deteriorate and she died two days before her 59th birthday.

**Dialogue**

**Opening the Discussion of DNR**

**Doctor:** A concern that a lot of us have, as oncologists, is that talking about DNR with a patient takes away hope. It can create a barrier in the relationship between us. I wonder, does the patient feel that we are giving up when we bring up DNR? However, if we don’t bring up DNR as an issue, are we doing a major disservice to our patients by not respecting their wishes as to how we should proceed? I also wonder what DNR status means to us? What does it mean to the patient? When should DNR be addressed? Who should ask for a DNR status? How does it affect our team?

**Doctor:** I don’t know if there is ever a good time to discuss DNR status. What I’ve learned, over the years, is to introduce the concept early in the relationship with the patient. This way, the patient can think about it, go home, and discuss it with his or her family. Then, as time goes by and your relationship with the patient strengthens, you can discuss DNR status again and come to a mutual decision about what the best status would be. The best plan changes over time, as treatments and options for therapy change. I often let the patient know that a decision does not have to be made today, but that eventually it will have to be made.

**Nurse:** I think that the most important thing is to listen to our patients and to the cues they give us, as to when they
seem ready—both physically and emotionally—to discuss DNR status; to listen for clues that indicate whether or not the patient would want to be resuscitated. Often these important cues are missed. At other times, because we are so rushed, we don’t communicate this information well to other team members.

**Doctor:** Frequently, the attending physician is absent and it’s the nurses and the house staff who are on the front-line and in the position of having to perform cardiopulmonary resuscitation (CPR).

**Nurse:** Do we perform heroic activities just because we haven’t had the chance to talk about it?

**Nurse:** I don’t like having to go after a doctor and say, “Look, you really need to address DNR because this man is really sick.”

**Doctor:** Why does it seem that the nurses want somebody to be DNR more than the doctors? What is so disturbing about putting a patient through a code? What bothers people about that?

**Nurse:** Well, I think a lot of it has to do with dignity. I walked in on a patient who was about to code (and she did code) and I said to the doctors, “This woman is basically dead. There is no way you are going to revive her. Do you have to tube her?” They said, “Yes, we’ve got to do it.” They had to go through the whole thing. I thought it was horrible. They should allow someone to die in the most comfortable way, if you know it’s going to happen. It is the most important thing. Give them some dignity. Let them go peacefully, rather than have their last moments be so dramatic.

**Doctor:** Do you think that patients suffer during codes?

**Nurses:** Yes, definitely.

**Doctor:** Interesting, because I have always been of the opinion that patients don’t really suffer during codes; most of them are dead before the code really gets going. The people who suffer most are the caregivers and the families.

**Nurse:** Especially if the patient is incapacitated, I don’t think that he or she feels physical pain, but I think that there are other types of pain. In the case of an incapacitated patient, I feel as if I am the spokesperson for that patient. I often ask myself, “If that were my mother or father or brother, would I want to disrespect them in this way? Does the end justify the means?”

### Helping the Patient and Family Reach the Right Decision

**Doctor:** In this case, from the standpoint of the physician, it seemed clear that we were not going to reverse this woman’s situation. However, we had a great deal of difficulty convincing her family that continued support was probably no longer indicated.

**Doctor:** Why was it so difficult for these people to accept this?

**Doctor:** One of the issues was the family’s lack of trust in the provider’s opinion. Her doctors had been wrong so many times; the family had heard about so many diagnoses and her prognosis changed almost from week to week.

**Social Worker:** The son said that what made it hard for him to agree with a DNR order, although he knew that his mother wanted it, was that he felt that his mother had surprised them every time. He hung on to the hope that this would again be something that she could get past.

**Doctor:** Does CPR even belong in the care of the terminally ill? On television, CPR is portrayed as a wonderful lifesaving procedure; in reality, survival to discharge or to functional status is unlikely. Statistics show this and we should educate our patients about these statistics when we discuss DNR status. When patients see this data, most refuse CPR. Should we be offering something that is of no clinical value and then make it seem like it is a decision for the patient to make?

**Nurse:** In order to prevent alienation and the loss of hope when designating a patient DNR, it is important to let the patient and the family know that there is still a treatment plan, but that it has changed. It is best to talk openly about the issue and to educate nurses and doctors about how to talk about it.

**Social Worker:** Rather than deal with the issue of DNR status so that the pressure of the moment controls what people decide, it is valuable to have a relaxed situation in which to reflect with one another.

**Nurse:** If you bring it up at the end when they are really sick, it is hard because it feels like suddenly there is a big
black cloud hanging over them. Whereas if you bring it up early in your conversations with the patient—before it is actually an issue—it’s as if a seed has been planted and allowed to grow as therapy continues.

**Nurse:** I think continuity, for our patients, is of great value. It gives the patient the courage to keep going. When the same familiar face is seen, they say, “Thank God it’s you. I know how you put the portacath® needle in,” etc., and I think that continuity needs to be carried through to the end, if it can be. Many times people die alone; I think that’s everyone’s worst nightmare. Nobody wants to die alone.

**Doctor:** But there are patients who do want to die alone because that’s the way they’ve been all their life. Therefore, I think that we have to be cautious when we are looking at how people want to die and consider how they’ve lived. Some people are very much loners and don’t want a lot of people around when they die. We have to be careful that we don’t put our own image of the whole death scenario onto our patients. Some of them want to die kicking and screaming because that’s how they’ve lived. We have to honor that and not feel bad if that’s how they die because that’s how they’ve lived.

**Nurse:** By law, nurses have to ask patients when they are admitted about healthcare proxies. Does anyone feel as if this could lead into a DNR discussion, making people aware of their choices?

**Doctor:** I think that using the discussion of healthcare proxies to introduce the thought, ‘what would I want done in a worst-case scenario,’ is a great idea. However, that approach may not be best for all patients. I don’t think that there is one solution for all patients, but rather each case must be looked at individually.

**Nurse:** To get down in the record what the patient wants helps to avoid making an issue of the family member who may have a different agenda with respect to CPR or DNR. For me, to clarify this early in a patient’s admission safeguards what the patient wants, and for me that is the most important thing.

**Doctor:** How do people feel about making it mandatory to address DNR status upon admittance? I find that when a patient tells me what he or she wants, that is much more important than who the healthcare proxy is.

**Nurse:** How about just a note in the chart from the attending physician about where you are in the discussion process? Because often we have no idea where the patient is in this thought process.

**Doctor:** I think that to require it, to force a decision on a patient at that point is probably inappropriate. Asking your patients whether they have decided this yet is worthwhile, and if they are undecided, even that information can be helpful.

**Doctor:** I have a problem with status being on the intake chart or order chart because I feel that staff do treat patients with a DNR status less aggressively. That’s just a reality. We have all had patients who were on the brink of death, but who in theory still have the chance for a cure; they just need to get through a rocky phase. They go to the unit and they come back from the unit. I do think that at 2 a.m., when the decision is being made whether to move someone to the ICU, staff are less likely to move a patient with a DNR status. I feel very uncomfortable with this. If I could be guaranteed that DNR would mean what it is supposed to, i.e., “I will not pump on your chest; I will not put a tube down your throat,” I would feel comfortable with it, but I think that DNR carries more weight than that.

**Judging Quality of Life for Others**

**Doctor:** A common concern in making decisions about DNR is the difference in opinion about what represents quality of life. What I might consider acceptable quality of life for myself may be very different to the quality that someone else might be willing to accept. I think her husband and, in particular, her son, were willing to tolerate what I did not think was an acceptable quality of life for her.

What is quality of life? I found the movie *Marvin’s Room* really helpful. It was a story about two sisters who have very different lives. One sister takes care of her demented and bedridden father. Her fun thing to do is to take a mirror and shine sunbeams around the room, and they sit there and giggle, just watching the reflections on the wall. The other person that she takes care of is an elderly, eccentric aunt whose idea of fun is to get dressed up to watch the soap operas. After 17 years of caring for these people, she develops leukemia and needs a bone marrow transplant. The other sister comes with her two sons to be typed to see if they are suitable donors, but they are not.
The sister with leukemia comments, “I’m a very lucky woman.” Here’s a woman who spent 17 years taking care of two people that couldn’t have been much fun. She has leukemia and she’s going to die. You wonder, why is she a very lucky woman? And her comment is, “Because I’ve experienced love in my life.” And her sister says, “Oh, yes, our father and our aunt love you very much.” But she says, “Oh, no, no, no, no, no. You don’t understand. You’ve missed my point. My point is that I have been able to love these two people, and I’ve been able to care for them, and so I’ve had love in my life.” Clearly, what others consider a good quality of life may be quite different from what our idea is.

**DISCUSSION**

In this case, although DNR status raised many issues, the central dilemma was resolved. The issue of obtaining a DNR status creates questions: Is CPR ever worthwhile as part of the care of patients with advanced cancer? Who asks the patient? When, how, and who makes the decision?

**Is CPR Worthwhile?**

CPR is frequently dismissed as fruitless in patients with advanced cancer. When CPR first became widely used in the 1960s it was advocated for the resuscitation of the victims of acute life-threatening, yet reversible, insults such as cardiac arrhythmias [1]. However, clinicians now consider what the likelihood will be that a cancer patient will survive CPR and be able to leave the hospital. One study reported that certain groups, such as those with a cardiovascular diagnosis, had relatively high survival rates (21% to 27%) post-CPR, while others, such as those with metastatic cancer, had no survivors to discharge [2]. Decision algorithms that predict success for CPR score heavily against patients with advanced cancer [3]; most doctors regard advanced cancer as a condition for which resuscitation is futile, despite reports of patients with malignant disease who have survived at least twelve months having undergone CPR [4]. This suggests that cancer patients as a group should not be excluded from CPR simply on the grounds that they have malignant disease; both their immediate and long-term prognosis should be taken into account [5].

**Discussing DNR Status: Who, When and How?**

Avoiding the topic of DNR status benefits neither the patient nor their caregivers; studies have shown that most patients are interested in decision making about resuscitation and want a clear mechanism or forum for expressing their wishes about resuscitation [6]. Despite many caregivers’ aversion to asking for a DNR status and concern that bringing up the issue of resuscitation may create a wall between doctor and patient, there is no evidence that such discussions undermine a patient’s or family’s confidence in their doctors [6]. The crucial issue is how CPR or DNR is discussed. Many clinicians believe that if the information is presented in a negative way, the patient can be deprived of a sense of hope. If that same information is offered in a sensitive way, with the emphasis on the care and comfort that will continue to be provided, hope can be preserved [7]. Indeed, such discussions may be better tolerated when the decision about whether CPR is an option is divorced from other treatment strategies that engender hope. In this way the decision about CPR becomes a part of a larger plan and the patient is less likely to feel abandoned. The decision about DNR status should reflect both the chance of meaningful survival and the philosophy of care. A helpful way to introduce these themes is to ask, “Is there something you’d want to survive with or without?” If you need to challenge what they appear to be denying, it is possible to negotiate talking about quality of life by asking, “Have you ever considered that sometimes life is not worth living?” Circumstances change and staff should attempt to gather all useful information at their disposal to facilitate an appropriate decision, and, in particular, the patient’s stated wishes.

**Who Makes the Decision?**

Some advocates attempt to simplify the discussion by reducing the issue to a clinical decision, not a moral one. However, this reasoning does not restrict the decision solely to objective parameters. It should take the patient’s emotional and psychological well being into consideration and weigh the worth of this potential intervention in the existential context of living and dying with cancer. It should be a decision upon which both the patient and doctor mutually agree, involving options for the best treatment [1]. Clearly, a record of excellent care and communication establishes the platform from which such discussions can be broached.
However, sudden and unexpected changes in health, iatrogenic complications, and uncertainty as to outcome, significantly complicate the discussion. It is important for the physician to ask the patient his or her wishes and to listen to nurses and social workers, with whom the patient may have established important relationships. One interview-based study of 23 patients with advanced cancer in hospice care reported that 52% of patients, but no nurses, were in favor of resuscitation [8]. Although opinions can be divergent, most decisions are made by consensus between physicians and the patient, the family or surrogates; major conflicts occur in only 1% of decisions to withhold life-sustaining treatment in incompetent patients [9].

Finally, although it is important for physicians to honor legal guidelines when making decisions about DNR orders, a physician’s decision should not be driven by fear of litigation [10]. Despite the seemingly stifling legal restrictions imposed on doctors, courts still value the “integrity of the medical profession.” This integrity is considered, however, to be tied to patient autonomy. In the end, the courts rightly value the wishes of the patient above the opinion of the physician. Although physicians may fear legal repercussions of not performing CPR on a patient, judicial decisions support the decision to withhold CPR when such treatment is futile, and when the physician acts in good faith and in accordance with good medical practice [11, 12]. If it is not possible to reconcile differences another physician, hospital or ultimately the courts can undertake an independent review. Many hospitals now have a committee, such as the Optimum Care Committee at the MGH, which reviews cases in which there is significant disagreement over the best treatment for a specific patient (i.e., when the patient’s family and caregivers disagree). Living wills are becoming more common, yet they are rarely specific enough, by themselves, to address the typically complex issues of resuscitation at the end of life; the appointment of a healthcare proxy may offer better protection of a patient’s wishes.

**Clinicians should remain mindful that their primary responsibility is to the patient and to the patient’s wishes.**

Discussions of how we feel about a patient or family (transference) and how our feelings are influenced by them (countertransference) need to be distinguished from reasonable differences of opinion. Reacting without insight can be avoided by clarification of the issues raised, and by exploration of the effect on the patient, the family, the staff and on ourselves. Such influences can subtly and powerfully influence the dynamics of the involved parties and alter the perception of what is actually said. While at times it is reasonable to explore why someone, such as the son, or the nurse (who felt the burden of responsibility to be the spokesperson of the patient) has certain needs, clinicians should remain mindful that their primary responsibility is to the patient and to the patient’s wishes. With family of patients who have the capacity to understand the issues and the implications of their own decision, it is reasonable to categorically defend the right of the patient to choose. The clinician can then ask family members to discuss their concerns directly with the patient [13].

**Conclusion**

When addressing the DNR status of a patient with cancer, it is important to balance the patient’s autonomy with the experience of the physician in whom they have invested trust, rather than putting all of the responsibility on the patient. The physician must listen to the patient and do what the patient wants based on her or his explicit or implied wishes. It is wise to discuss end-of-life issues early on in the patient-doctor relationship to prevent decisions being made hastily in a crisis. Open and comprehensive discussion enables patients to make informed decisions. Circumstances and views may change and when patients are not competent the decision should reflect all of the available information. Caregivers should be mindful to “cure sometimes, relieve often, and comfort always” [1]. The goal should be to trump the Golden Rule of “doing unto others, as we would have them do unto us” by doing unto others what they want done to them.

**Acknowledgment**

We very much appreciate the contribution of Carolyn Wood, legal counsel for Partners Healthcare in the Office of the General Counsel at MGH.
REFERENCES


ADDITIONAL READING


