

# The surrogate's experience in authorizing a do not resuscitate order

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(RECEIVED December 6, 2006; ACCEPTED May 4, 2007)

## ABSTRACT

*Objective:* Little is known about the subjective experience of surrogates who authorize do not resuscitate (DNR) orders. This experience seems especially acute in settings such as New York State, where patients and surrogates generally give written consent for DNR orders. The goal of this study is to investigate the subjective and emotional experience of surrogates who authorize DNR orders in this setting.

*Methods:* A qualitative, phenomenological research design was used. Surrogates of patients on the medical service were approached no earlier than 1 day and no later than 7 days after authorizing a DNR order. The interview guide was open-ended and included general prompts. Interviews were taped and transcribed. Researchers then coded the transcripts and examined the data for clusters of themes. They then met to discuss and recode disagreements.

*Results:* Saturation was met after 10 subjects were interviewed. The following major surrogate themes were found: (1) Signing a DNR order is a process, not an isolated act. (2) The presence or absence of good quality communication and psychological support from health care personnel are among the most important factors in this process. (3) The process of signing a DNR order can raise many negative emotions including guilt, ambivalence, and conflict. (4) Prior discussions, documents such as living wills, and consensus among family members make it easier to determine the patient's wishes and carry them out by signing the DNR. (5) The surrogates believed that signing a DNR order is a prerequisite to obtaining adequate opioid analgesia.

*Significance of results:* The experience of authorizing a DNR order is a complex and emotional decision-making process. Evidence of the patient's prior wishes and support from health care personnel make the process easier. It is disconcerting that surrogates viewed DNR orders as a prerequisite to obtaining relief for a patient's pain or suffering.

**KEYWORDS:** Surrogate, Communication, Do not resuscitate orders, Ethics, End-of-life care

## INTRODUCTION

Patient participation in end-of-life (EOL) care has become normative in the United States (Rein et al., 1996; Ersek et al., 1998). The intense research and policy interest in the role of the patient in this process, however, may be missing the mark. For example,

although the Federal statute addressing this issue is entitled the Patient Self-Determination Act (Dimond, 1994), in practice, patients at the end of life often cannot make decisions for themselves. Surrogates must decide for them, regardless of whether advance directives have been executed. In fact, the majority of do not resuscitate (DNR) orders are authorized by surrogates, not patients (Hansen et al., 1994; Sulmasy et al., 1996). Many patients who lack capacity to participate at the time of DNR decision making were able to do so 2 weeks before (Wenger et al., 1994). Concerns

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have also been raised about the accuracy of surrogates' substituted judgments (Hare et al., 1992; Layde et al., 1995; Sulmasy et al., 1998). Recent studies have begun to document that surrogates' decisions to withdraw life-sustaining treatments are associated with high levels of stress (Jezewski & Finnell, 1998; Tilden et al., 2001; Sulmasy et al., 2006). However, little is known about the sense-making dynamic and emotional state of those making EOL decisions on behalf of others. Previous qualitative work has focused on the cognitive and social aspects of family decision making (Jacobs, 1998). Less is known about the dynamics and emotional experiences of surrogates. What are the causes of their stress? What meanings do they attach to their decisions? Better understanding of surrogates' decisions might be very important in improving the quality of decision making at the end of life, because they make the majority of decisions. In the present study, we used a qualitative, phenomenological approach to provide an in-depth account of the surrogate DNR decision-making process.

## Background

Although most states simply accept DNR orders as part of standard medical practice, some states, such as New York and Oklahoma, are unusual in having explicit DNR statutes (New York Public Health Law, 1987; Oklahoma Do Not Resuscitate Act, 2005). Under New York state law, resuscitation is legally required unless actively refused by the patient or surrogate (Lederberg, 1997). In addition, for many reasons, including fear of litigation, the vast majority of New York hospitals require a signature from the patient or surrogate should they choose to be DNR despite the fact that the state law only requires a consent (written or verbal) with appropriate documentation (Jezewski & Finnell, 1998). The formalized ritual of approaching a loved one about "signing a DNR order" has made the procedure a liminal event in New York, creating a model situation for studying the experience of surrogates who find themselves making decisions about life-prolonging treatments for their loved ones.

## METHODS

### Research Design

The question we were most interested in was, "What is the experience of authorizing a DNR order as a surrogate?" To reconstruct the decision-making process, we asked: "What are the events and feelings experienced by the surrogate when first approached about a DNR order, when signing a DNR order, and after signing a DNR?"

A phenomenological research design was used. Phenomenology is both a philosophy and a research method. As a research method its main objective is to examine and describe phenomena as they are being experienced. Phenomenological research eschews *a priori* causal theory and requires data collection and interpretation to be as free as possible from unexamined preconceptions and presuppositions (Spiegelberg, 1979; Hull et al., 2001). To achieve the goal of being as free as possible from unexamined preconceptions and presuppositions, the researchers should examine all of their thoughts regarding the phenomenon being studied and then set them aside. This process is called "bracketing" (Oiler, 1998).

Phenomenological methodology calls for exploring the phenomenon with a sample until data saturation is reached. The convention is to begin with a sample of 10 and continue to sample if data saturation has not occurred. The surrogates were selected as described below.

### Subject Recruitment

One of the researchers (C.H.) attended the Nursing Leadership meetings at the research site and explained the study to the nursing staff. She then made rounds on the nursing units three times a week asking for the names of patients who had a DNR form signed by a surrogate. Another author (W.A.U.) contacted the medical Chief Residents for the names of patients who had been made DNR. In both situations, the Principal Investigator (C.H.) discussed the patient/surrogate situation with the nursing staff to ensure that there were no contraindications to the surrogate being approached. C.H. then gave the patient's name and location to a Research Assistant (RA), who then contacted the surrogate about participating in the study. The RA initially made contact with the surrogate in person or by telephone. If the surrogate agreed to participate, an informed consent was signed. The St. Vincent's Institutional Review Board approved this study.

### Inclusion and Exclusion Criteria

Eligible subjects for the study were patient surrogates who had signed DNR orders within the previous 25–96 h. We attempted to contact all potentially eligible subjects at the research site within the period of the study. In accordance with ethical and IRB concerns, subjects were excluded if the nursing staff determined that being approached for the study would cause undue stress. As a result, six potential subjects were excluded from the sample pool. Some surrogates could not be contacted, and in many cases the patient was discharged, transferred, or died before the surrogate could be contacted.

## Sample

During the data collection period, 22 subjects were eligible for the study. Of these, 12 did not consent to participate in the study. The final number of subjects for the study was 10. We approached the surrogates of non-critical-care patients on the medical service. Eight subjects spoke English and two spoke only Spanish. The RAs, who were fluently bilingual, immediately translated their questions and the subjects' answers into English and subsequently reverified the content with the subjects. Four of the subjects were white, four were Hispanic, and two were African-American. When asked about religious preference, six subjects indicated Catholic, one Jewish, one Protestant, and two indicated "other." Eight of the subjects did not attend church/temple; two did. Eight of the subjects had reported experiencing the death of a first-degree relative, and in two of these cases the member reportedly received hospice services.

## Interview Procedure

The surrogate was presented with a series of open-ended qualitative research questions asking the participant to describe how he or she was first approached about the DNR order and how she felt about the event, as well as how she felt when signing the DNR order. Throughout the interview, researchers used verbal prompts to elicit as much information as possible. Words that elicited prompts included expressions of affect, such as "I felt," or "It feels," positive or negative words such as "It was awful," and emotional words such as "angry," "sad," "peaceful," and so forth. Probes such as, "Tell me more about this," "You said this made you angry," and "Can you tell me more about that?" were then used until the surrogate had nothing more to say. To minimize researcher influence on the respondents, the RAs were asked to "bracket" knowledge and feelings about the subject prior to each interview and to refrain from expressing them during the interviews.

Interviews were conducted in person in a quiet room/office away from the Nursing Unit. Privacy was assured. All interviews were taped. Each tape was then transcribed and analyzed. Data collection continued until repetition of data occurred without any new themes.

## Data Analysis

The data were analyzed according to the techniques of phenomenological research (Morse, 1989). C.H. listened to each tape and read the corresponding transcript in its entirety to assure accurate transcription. The transcript was read again to get the general

sense of the interview. Each transcript was read in detail, and significant phrases or statements that pertained to the experience were extracted. These statements and phrases were examined and coded for meaning. The codes were then arranged in clusters of themes. At each phase of the analysis the findings were reviewed with a master's prepared (doctoral candidate) nurse (C.M.) with experience in qualitative research. Agreement was reached between C.H. and this independent reader. Numerous quotes are included in the results of the study to provide richness of data.

## RESULTS

### Themes

After extensive reviews of the codified interview transcripts, five themes consistently emerged from the data that illuminate the dynamics and emotional experiences of the surrogate decision-making process:

1. Signing a DNR order is a process, not an isolated act.
2. The presence or absence of good quality communication and psychological support from health care personnel are important factors in this process.
3. The process of signing a DNR order can raise many negative emotions, including guilt, ambivalence, and conflict.
4. Prior discussions, documents such as living wills, and consensus among family members make it easier (for the surrogate) to determine patients' wishes and carry them out by signing a DNR order.
5. Signing a DNR order is helpful in obtaining relief for a loved one's suffering, i.e., surrogates viewed it as a prerequisite to getting adequate opioid analgesia.

### Theme 1: Signing a DNR Order Is a Process, Not an Isolated Act

Participants went to great lengths to describe the steps that had taken place from the time they were first approached to sign a DNR order until they finally signed the document. The details of the steps taken were different for each subject, depending on the particular circumstances of the patient's situation. It was clear, however, that all surrogates experienced signing a DNR as a process. No subject signed the document when it was first presented, even in cases in which the patient had clearly

expressed wishes about resuscitation. They described a process of accepting their loved one's prognosis, and a process of preparing for their loved one's death.

According to the subjects, the time taken to arrive at the DNR decision is helpful for reaching a satisfactory outcome. One patient's daughter noted:

I appreciated this time because it gives it a kind of ordered way. It's not chaotic and frenetic with all of that . . . . It was a wonderful time of preparation because I was able to call the funeral home, but she had made her own arrangements. She had picked out a dress. So it was an opportunity for education and planning in a way that I wouldn't have if there was a heart attack.

Another patient's daughter, who was a nurse, emphasized the temporal importance of the decision-making process:

Sometimes you go to the hospital—I'm talking like a lay person, not like a professional—sometimes you have to give them time. You approach them, but they have to get used to the idea of what's going to happen to their loved one . . . and you have to give the family time to grieve and make a decision. Not to rush them.

### **Theme 2: The Presence or Absence of Good Quality Communication and Psychological Support from Health Care Personnel Are Important Factors in This Process**

Subjects described what they felt were examples of good communication and support from their health care team and indicated that communication and support helped to ease the emotional distress associated with signing a DNR order. According to one subject who felt supported by the team:

I felt that the medical staff there, the doctors and nurses, were very responsive to my requests for questions and that they were doing their best to help.

Another subject recalled how support from the nursing staff helped affirm the DNR decision:

And when the nurses saw the DNR order . . . that's good. So we were getting support from them that we made a good decision.

Respondents were also able to describe what they saw as hindrances to communication and to relate the anger and frustration they felt in these situations. One

surrogate, who had expressed a good deal of anger said,

They never explained to us that [a DNR] was available. We had to figure that out for ourselves. I think if the family that's in a situation like this is making decisions for someone who can't, we need all the information we can to make an informed decision. So all the decisions we made on our own. Nobody helped us.

Some subjects also suggested that the health care team was ineffective or believed that other staff members were discussing the issue with patients when, in fact, no one was. This can be summed up by another participant, who stated, "Everybody thought they were communicating but they weren't."

### **Theme 3: The Process of Signing a DNR Order Can Raise Many Negative Emotions Including Guilt, Ambivalence, and Conflict**

Because the DNR decision is an emotionally laden and complex process for surrogates, it is important to understand the negative emotions associated with the decision-making process. As described by one mother on signing a DNR order for her daughter, "I felt guilty if I didn't because she would suffer; I felt guilty if I did because she would die. This is my child. When your child hurts, you hurt."

One participant, a surrogate for her mother, also expressed the complex emotions associated with the DNR decision:

Sometimes you do feel guilty, if you're doing the right thing or not . . . . Shall I go with what she wants or how I'm feeling now. I was feeling that you're going to lose . . . . It's like her life is in your hands. Maybe she would have had a chance. You don't know what's going to happen.

Another daughter admitted, "I felt as if I was like in my own heart hoping that she would just hurry up and die. Not that I wanted her to die, but so that I wouldn't have to go through what I'm going through."

### **Theme 4: Prior Discussions, Documents such as Living Wills, and Consensus among Family Members Make It Easier (for the Surrogate) to Determine the Patients' Wishes and Carry Them Out by Signing the DNR Order**

Subjects indicated that prior discussions with the patients as well as family discussions, including disagreements and consensus formation, helped with the emotional burdens of the decision-making

process. Often the surrogate was the primary person with whom the patient had discussed end-of-life issues, as exemplified in one husband's remarks, "So the next time she's in the hospital it's up to me to sign it. I know that's what she wants. She's made that very clear."

A participant, the wife of the patient, stated, "Because my husband was sick a lot and because I had discussions with other family members, that helped me to sign the DNR, and, as a result, when I was signing the form it was a peaceful process."

One participant, a daughter, related the discussions she and her sister had with their mother:

Because we were able to talk to my mother before the surgery, a lot of decisions are based on what she wanted. She did a living will and was very clear she didn't want to be on any mechanical means.

Another surrogate noted that the family was "all in agreement, all the same, all consensus, but no one wanted to be the first one to say it, I guess."

A subtheme mentioned by the subjects was that prior experiences with family members at end of life had helped with decision-making: "My father, . . . they had put him on a machine and my mother had that taken off because he had already been gone a couple of hours. We don't want to see him [the patient] like that."

### **Theme 5: Surrogates Perceive the Signing of the DNR Order as Helpful in Obtaining Relief for a Loved One's Suffering; Some Surrogates View It as a Prerequisite to Obtaining Adequate Opioid Analgesia**

In describing the process of signing a DNR order, many subjects describe the realization that the patient was suffering as an important factor in the decision-making process. It seemed to be an acknowledgment that the person was actually dying. It was more difficult to decide that someone who was clearly dying, but comfortable, should not be resuscitated.

One surrogate described the patient, "She's told me she's ready to go. She's ready to leave this life, that she's tired and she doesn't feel well . . . She kept saying that she was ready, this was no life." A wife described her husband: "He was suffering. He's been here for about 2 months and he's suffering . . . He hardly talks and I don't want to see him like that." Another participant, a daughter, noted:

At first I was scared, but then I realized that this was the right thing to do, as my mother was already suffering. I knew that signing the form was my way of acknowledging that she was dying.

More disturbing was the subtheme that some subjects expressed that it was only by acknowledging that the patient was dying (through a DNR order) that the patient could receive adequate opioid analgesia. One daughter stated:

I read the forms and signed them. Then, what was wonderful, she would get the morphine as she needed it. People at work used to talk about their mothers, also, and it was hard, they couldn't get the morphine. They didn't get it, they had to fight all the time because of fear of addiction.

Another daughter said:

I guess if you don't sign it [the DNR] they don't give you enough painkillers. I guess that's what the law allows . . . We're not worried about her being addicted at this point.

## **DISCUSSION**

For this group of surrogates, signing a DNR order was viewed not as an isolated act but as a process, one that can raise many mixed emotions. Prior discussion, documents such as living wills, and consensus among family members can make this process easier. Other variables that can affect this process are presence or absence of communication and support by the health care team, as well as a belief that signing a DNR order can be helpful in obtaining relief for a loved one's suffering.

Perhaps the most important finding of this current study is that surrogates view signing a DNR order as a process. Professionals may harbor unrealistic expectations that a decision about DNR orders will occur following a brief, efficient, one-time meeting. Our findings also indicate that the DNR decision-making process should begin earlier in the patient's course so there may be more time available for surrogates to arrive at a decision. Sufficient time would allow the process to unfold rather than pressuring the family when the disease has progressed but DNR discussions have not kept pace. Some surrogates need to review what the patient and/or family has experienced in the past with end of life issues. Some need to review written documents such as living wills. Some need to spend time in discussion with family members. Some need to see that their loved one is not going to get well and may be suffering.

What is the role of the health care team in this process? The foremost role that health care team members can serve seems to be to provide good quality communication and psychological/social support. The fact that health care professionals must often

approach surrogates as strangers complicates this role, but does not vitiate its importance.

The surrogates in our study indicated that on several occasions members of the health care team seem to have believed that someone else had initiated a discussion about DNR orders when, in fact, no one had initiated such a discussion. Everyone who cares for the patient ought to know who is responsible for conducting EOL discussions and be aware of the stage to which such discussions have progressed. This will require a combination of verbal communication and good charting.

It may also be valuable to inform surrogates that negative feelings such as guilt, conflict, or anxiety are common in such circumstances and to offer them a chance to discuss these feelings. Striking a balance between giving support and information and merely telling the surrogate what to do can be delicate. Subjects in this study were relieved to hear the nurses tell them that they had made the right decision. They may need to hear that they have performed a difficult task and have done the right thing for their loved one. Some may even require therapeutic intervention or referral to clergy, social workers, or counselors.

Finally, this study shows that surrogates, even today, may harbor the belief that one can only obtain relief for one's suffering if a DNR order is written. This belief may be left over from the days when we "saved the morphine for the end." It may be a belief perpetuated by the media. Perhaps it is indirectly communicated or reinforced by comments and attitudes of staff. That fact that this myth persists, however, suggests a need to educate patients and their families early in the course of the patient's illness about the need for adequate analgesia. Patients and their loved ones need to be assured that pain and symptom management is as much a priority as life-sustaining interventions. Staff education about the appropriate use of opioids should be ongoing. The message should be loud and clear that we do not "save the morphine for the end."

### Limitations of the Study

Because this is a phenomenological study, the results are not meant to predict, but, rather, to provide an in-depth account of the surrogate decision-making experience. For this reason, the data should be narrowly interpreted as descriptive of the experience of this group of surrogates. Typical of qualitative research, the research is limited by a sample size and its use of a single location. Moreover, the New York environment is atypical because of the use of signed DNR consent forms. However, we believe this setting merely provides a good model for

studying a phenomenon that we suspect is similar in other settings. The richness of our data and the depth of our analysis have independent value.

### Suggestions for Future Research

Future studies might explore the same questions in different legal and cultural settings. Studies examining surrogates who chose to not sign authorize a DNR order even though the health care team discussed it with them might contribute fruitfully to the literature as well. Research regarding these variations will further illuminate the surrogate decision-making experience.

### CONCLUSIONS

This study portrays the experience of signing a DNR by a surrogate not as an isolated act but as a process, one that can raise many negative emotions. Prior discussion, documents such as living wills, and consensus among family members can make this process easier. Other variables that can affect this process are presence or absence of communication and support by the health care team, as well as a belief that signing a DNR can be helpful in obtaining relief for a loved one's suffering. The surrogate's ordeal deserves much more attention from investigators as well as clinicians. We need to strive to support these persons throughout the decision-making process and to relieve the suffering and pain of their loved ones no matter what decision they ultimately make.

### ACKNOWLEDGMENTS

We are very grateful to M. Kai He for her assistance with manuscript preparation and to Sean Nagle for his assistance with interviews.

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