Why Do Patients Agree to a “Do Not Resuscitate” or “Full Code” Order? Perspectives of Medical Inpatients

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BACKGROUND: The majority of patients who die in hospital have a “Do Not Resuscitate” (DNR) order in place at the time of their death, yet we know very little about why some patients request or agree to a DNR order, why others don’t, and how they view discussions of resuscitation status.

METHODS: We conducted semi-structured interviews of English-speaking medical inpatients who had clearly requested a DNR or full code (FC) order after a discussion with their admitting team, and analyzed the transcripts using a modified grounded-theory approach.

RESULTS: We achieved conceptual saturation after conducting 44 interviews (27 DNR, 17 FC) over a 4-month period. Patients in the DNR group were much older than those in the FC group, but they had broadly similar admission diagnoses and comorbidities. DNR patients reported much greater familiarity with the subject and described a more positive experience than FC patients with their resuscitation discussions. Participants typically requested FC or DNR orders based on personal, relational or philosophical considerations, but these considerations manifested differently depending on the participant’s preference for resuscitation. Most FC patients stated that would not want a prolonged period of life support, and they would not want resuscitation in the event of a poor quality of life. FC and DNR patients understood resuscitation and DNR orders differently. DNR patients described resuscitation in graphic, concrete terms that emphasized suffering and futility, and DNR orders in terms of comfort or natural processes. FC patients understood resuscitation in an abstract sense as something that restores life,

while DNR orders were associated with substandard care or even euthanasia.

CONCLUSION: Our study identified important differences and commonalities between the perspectives of DNR and FC patients. We hope that this information can be used to help physicians better understand the needs of their patients when discussing resuscitation.

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INTRODUCTION

The majority of patients who die on a medical ward have a “Do Not Resuscitate” (DNR) order in place prior to their demise¹. These orders are typically written after a discussion between a physician and the patient or his/her surrogate decision-maker.

We know little about these conversations—only that physicians and patients feel uncomfortable with them^{2–4}, and that they are highly variable in terms of timing⁵, content^{6–9}, and style^{10,11}. As a result (and understandably), many physicians do not know their patients’ preferences for resuscitation¹, and many patients have a very poor understanding of their own resuscitation order^{2,12}.

We also know little about how patients view these conversations, and why patients ultimately choose a “DNR” or “Full Code” (FC) order. This information would be helpful to inexperienced clinicians and those who have these conversations on a regular basis; clinicians would better appreciate the concerns of their patients, and may better understand the root causes of conflict and discordance around resuscitation orders. In order to learn more about patients’ perspectives, we conducted a qualitative study of medical inpatients who had recently participated in a conversation about their resuscitation order.

METHODS

We used qualitative case study methodology to collect and analyze information about discussions of resuscitation orders with patients admitted to medical wards. Qualitative methods are appropriate for this subject, as resuscitation conversations

JD, RWS, JM, and LH all contributed to study design. JD and TL conducted literature searches. JD, TL, and RWS conducted the interviews and analyzed the data. All authors participated in data interpretation. JD wrote the original manuscript, and all authors participated in critical revision.

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are complex social phenomena¹³. Our study protocol was approved by the Research Ethics Boards of the University Health Network and Mount Sinai Hospital in Toronto, Canada.

Participants

Over two time periods (July–August 2006 and March–April 2009) we enrolled patients who were admitted to the medical wards of three academic tertiary care hospitals in Toronto, Canada (Toronto General Hospital, Toronto Western Hospital, and Mount Sinai Hospital). Every morning during the enrollment period, we reviewed the list of patients admitted over the previous 24 h along with the admitting team and screened the list for patients who met our inclusion criteria. We also reviewed a list of patients admitted previously to the same team to screen for patients who were not enrolled at the time of admission but now met our inclusion criteria.

Our inclusion criteria were: (1) the patient must speak English well enough to provide informed consent to participate in the study; (2) the patient must be capable of providing informed consent for participation in the study and for their resuscitation order; and (3) the patient must have had a discussion with the admitting team during the current admission about his/her resuscitation order and clearly requested either full resuscitation (FC) or no resuscitation (DNR). We excluded patients who were judged by the admitting team to be imminently dying or emotionally unable to tolerate a discussion of their resuscitation order.

Interviews

After obtaining informed consent, we conducted a semi-structured interview using a question guide that was developed for the study. All interviews were conducted face-to-face, digitally recorded, and professionally transcribed with any identifying information removed from the transcription. All interviews were conducted by either an ICU-based physician (JD, TL) or researcher (RS), or a trained research assistant with experience in qualitative methods (NA). The initial six interviews in each enrollment period were observed by a second interviewer in order to ensure a similar technique in subsequent interviews. Interviews lasted approximately 10–30 min. We continued enrolling subjects in the second enrollment period until we had achieved conceptual saturation for both DNR and FC patients. Admission diagnoses and comorbidities were recorded based on the admission note in the medical record.

Analysis

We analyzed the interview transcripts using a modified grounded theory approach. We used the interview guide to identify the initial coding themes and modified these initial themes during analysis to reflect the codes obtained from the transcripts. We began by using open coding to identify concepts from the interviews, and then we organized these

concepts into sub-themes and themes using axial coding (during which time the initial themes were modified). We performed our analysis concurrently with data collection. Two authors (JD and TL) performed an independent analysis of the first 24 interviews, then compared coding schemes. After resolving differences in the coding schemes, JD and TL analyzed the remaining transcripts independently and compared coding schemes again to achieve consensus for the final coding scheme. The final coding scheme and transcripts were reviewed by a third author (RS).

RESULTS

Forty-four patients met the inclusion criteria and gave consent to participate in the study. Demographic data were collected during the second enrollment period (31 patients) and appear in Table 1. The admitting diagnoses and comorbidities were broadly similar between the two groups, although there was a large difference in mean age.

Two interviews were excluded from the analysis; one because it was terminated at the request of the patient, and one because the interview revealed that the participant clearly did not understand the resuscitation order that he/she had requested. We achieved conceptual saturation for DNR patients after 26 interviews and for FC patients after 16 interviews.

Familiarity with Resuscitation and Reaction to Conversation

DNR patients reported a much greater familiarity with resuscitation discussions than FC patients. This was typically due to previous conversations with health care professionals,

Table 1. Patient demographics

Characteristic	Full code (15)	DNR (14)
Age (mean (SD))	57.2 (12.9)	76.2 (12.9)
Gender (% male)	66.6	64.3
Admitting diagnosis		
Cancer-related	4	4
Nonmalignant disease		
Heart disease	1	2
Lung disease	1	3
Liver disease	1	0
Stroke/neurologic disease	1	2
Gastrointestinal hemorrhage	1	1
Other		
Infection	3	0
Venous thrombus/thromboembolism	3	0
Abdominal pain NYD	0	1
Myeloproliferative disorder	0	1
Comorbidities		
Cancer	4	4
Nonmalignant disease		
Heart disease	5	6
Lung disease	2	4
Liver disease	2	0
Stroke/neurologic disease	3	2
Renal disease requiring hemodialysis	1	0
Other		
Hemophilia B	1	0

experiences with relatives, or self-realization prompted by other experiences. Relatively few had never discussed the issue before, and only one reported never having thought about it. FC patients, on the other hand, typically reported no previous experience with this discussion, although a few had discussed it previously on admission to hospital.

Consistent with this finding, many of the FC patients were surprised by the conversation or felt that it should not have taken place. Some reported that the discussion was disturbing or that it elicited fear of their own mortality. The vast majority reported negative or neutral reactions to the conversation. Two FC participants reported a positive reaction—both expressed satisfaction about the respect for their autonomy.

In contrast, the DNR patients generally reported a more positive experience. Some DNR patients were still shocked by the conversation, but many felt that it was necessary and appropriate. A handful were happy despite being given a poor prognosis during the conversation—they were happy to have a clearer idea of the future, even if the news was bad.

I feel good I because I know that they are looking after me...They are really telling me the bottom line, that there is nothing left here...That's good because you know what to look forward to.

Why Patients Chose FC or DNR

Table 2 shows the coding scheme for the logic underlying resuscitation decisions. Participants made their decisions based on three considerations: (1) personal factors reflecting lifestyle or health status; (2) relational factors—either to family or society as a whole; (3) philosophical factors—reflecting what they felt to be "appropriate." In general, DNR patients gave more well-developed answers than FC patients. Examples of quotes are shown.

Both FC and DNR patients reported similar personal factors that guided their decision-making: health status, functional status, and quality of life. DNR patients either felt that these factors were currently not satisfactory for them or that resuscitation/life support would lead to such a state. Some were concerned about the pain associated with resuscitation. FC patients, on the other hand, felt that these factors were all satisfactory. However, many qualified their answer by saying that they would not want resuscitation if they had a poor QOL or health status. Some stated that they would not want a prolonged period of life-support.

Relational factors were divided into familial and societal considerations. DNR patients expressed a desire to avoid resuscitation in order to lessen the emotional burden on family members. FC participants requested resuscitation in the hope of remaining with family members. Only DNR patients cited societal considerations. Some were concerned about the burden that their resuscitation and life support would place on health care workers. Others were concerned about the financial costs to society as a whole.

Finally, some participants cited philosophical reasons for requesting a DNR or FC order. Some DNR patients expressed discomfort with the idea of life support, while others spoke

Table 2. Reasons for choosing DNR or FC orders

• Personal factors
◦ DNR patients
▪ <i>Unsatisfied with present QOL/health status</i>
• "I can't stand up by myself out of bed, I need help with everything so what's the sense to try to keep on living?"
▪ <i>Poor anticipated QOL/health status</i>
• "If my life was going to be spent in this room forever...no thanks"
▪ <i>Pain associated with resuscitation</i>
• "If I only have 3 more months, I don't really want to have any more pain"
◦ FC patients
▪ <i>Good current QOL/health status</i>
• "I like life...life has been very good to me"
▪ <i>Decision dependent on QOL/Health Status</i>
• "I think it all depends on...the quality of life you have left"
• "I lost my wife to cancer 5-6 years ago and we put a do not resuscitation order for her because it was inevitable anyway"
▪ <i>Do not want prolonged life support</i>
• "I wouldn't take the machine that would keep me going for a period of time"
• Relational factors
◦ Family
▪ <i>DNR—Desire to avoid emotional burden on family members</i>
• "It causes hardship for my family"
▪ <i>FC—Desire to remain with family members</i>
• "The first thing I thought of was my daughter, then I said, yes...yes, resuscitate me"
◦ Society
▪ <i>DNR—Concern about burden to health care workers</i>
• "If I'm going to live on a machine, somebody will have to look after the machine, and I don't think that's fair"
▪ <i>DNR—Concern about burden to society</i>
• "It bothers me that society is paying all this money to stay alive"
• Philosophical factors
◦ DNR patients
▪ <i>Discomfort with the idea of life support</i>
• "I don't want to be kept artificially alive...when the body cannot sustain you, you are dead"
▪ <i>Inevitability of death</i>
• "If I'm dying, let me die. You can't change something that is irrevocable"
◦ FC patients
▪ <i>Unfulfilled life goals</i>
• "I said you just do what you have to do to keep me alive. Because there is a lot that I want to do"
▪ <i>Resuscitation as standard of care</i>
• "I would want to be resuscitated. If I didn't, then why would I come to the hospital?"

about the inevitability of death. Some FC patients, on the other hand, cited a need to accomplish life goals. One participant spoke about resuscitation as the standard of care—something (he/she felt) that all patients must want if they present to a hospital.

Participants' Understanding of Resuscitation and DNR Orders

FC and DNR patients had very different understandings of resuscitation and DNR orders, and there were few common themes identified in their answers (Table 3). DNR patients described resuscitation as a violent or traumatic event, associated with "tubes" or "machines," painful, and generally futile. FC patients, on the other hand, often described

Table 3. Patients' Understanding of "Resuscitation" and "DNR orders"

<ul style="list-style-type: none"> • Resuscitation <ul style="list-style-type: none"> ◦ DNR patients <ul style="list-style-type: none"> • Violent, traumatic CPR <ul style="list-style-type: none"> • "You'll have a bunch of people jumping on your chest" • Tubes and machines <ul style="list-style-type: none"> • "They put the tube down your throat, and there are complications that often set in after that" • Pain associated with resuscitation <ul style="list-style-type: none"> • "What I heard was pain, pain then, and pain when and if I survive" • Futile prolongation of life <ul style="list-style-type: none"> • "I think resuscitation means 'make the person suffer for a few days more'" ◦ FC patients <ul style="list-style-type: none"> • Abstract "restoration of life" <ul style="list-style-type: none"> • "It means bringing them back to the point when they will at some point be conscious" • Concrete <ul style="list-style-type: none"> • "Where they are shocked, their heart is restarted again" • No clear idea <ul style="list-style-type: none"> • "No idea, no one explained that to me, I don't know" • DNR orders <ul style="list-style-type: none"> ◦ DNR patients <ul style="list-style-type: none"> • Comfort care <ul style="list-style-type: none"> • "They would do everything medically possible, you know, for your breathing and in keeping you comfortable" • Allow natural process <ul style="list-style-type: none"> • "Let nature take it's course, sometimes it's just best way" • Active treatment with judgment <ul style="list-style-type: none"> • "I'm quite willing to put myself in your hand and try everything if it's going to help my condition...if they can do anything to take me back to what I was before" ◦ FC patients <ul style="list-style-type: none"> • Passive/suboptimal care <ul style="list-style-type: none"> • "I had brother in-law...he took ill at the home and they took him into emergency, and they left him there...he passed away...They didn't give him the proper attention...and that's what I feel it would happen if you say no resuscitation" • "Sit there and die" • Euthanasia/assisted suicide <ul style="list-style-type: none"> • "Well, I almost feel like we are getting into euthanasia here" • Compassionate care <ul style="list-style-type: none"> • "Just caring about the body, being human being for another person, just show that you care"

resuscitation in a more abstract way: the "restoration" of life. A small number described some concrete aspects of resuscitation, but usually not in a violent sense. Finally, a small number admitted frankly that they had no clear idea of what resuscitation actually was.

Consistent with these answers, DNR patients described DNR orders in terms of "comfort care" and allowing "natural" processes to take place. Some explained that their doctor(s) would still attempt to treat them medically, but with a view to limiting more aggressive treatments. FC patients mostly felt that a DNR order would lead to substandard care or neglect, and three felt that it would lead to euthanasia or assisted suicide. Only two described comfort care, and one explained that the patient would still receive other indicated therapies.

Family Involvement

Both DNR and FC patients reported thinking about their family members when deciding whether or not to request resuscitation. DNR patients had frequently discussed their

resuscitation order with their family, but all reported making the final decision themselves and receiving support from their loved ones. FC patients usually did not involve family members unless they were present during the conversation with the physician.

DISCUSSION

In this study, we used qualitative methods to study a large group of patients who had recently participated in a conversation about their resuscitation order, in order to learn more about their perspectives and decision-making rationale. Previous qualitative studies in this area have identified important considerations for DNR orders among outpatients with cancer^{14,15}. In our study, we focused on the resuscitation discussion itself and the reasons why medical inpatients request a "full code" or "do not resuscitate" order. While many experienced clinicians would recognize the themes we identify, this study serves to document explicitly what many have found anecdotally. This study also provides insight for less experienced clinicians.

Our study identified a number of important differences between DNR and FC patients in terms of perspective. DNR patients often had previous experience with resuscitation discussions from family members, previous admissions, or self-realization, whereas FC patients had often never discussed the subject prior to their current admission. The DNR patients were much older than the FC patients and would therefore be more likely to have accumulated such experiences. However, most medical inpatients have not previously discussed resuscitation with a physician, even in cases of advanced or terminal illness^{2,3}.

Some DNR patients wished to forego CPR in order to avoid anticipated pain or a poor quality of life. Consistent with this logic, many understood resuscitation in graphic and concrete terms that emphasized "machines" and "tubes," while others described resuscitation in abstract terms as something that emphasized suffering and a futile prolongation of life. In contrast, many FC patients requested resuscitation in the hope of staying alive to spend time with family or fulfill personal goals. Accordingly, they generally understood resuscitation in an abstract sense as something that restores life, presumably with a high level of function. They almost always qualified their FC order by saying that they would not want resuscitation if they were older or had more advanced disease (presumably due to a poorer level of function), and they would not want to be kept on life support for a prolonged period following resuscitation.

These findings are notable because both FC and DNR patients felt that a DNR order would be desirable in cases of advanced age, or poor quality of life and overall health. These factors are subjective and variable over time, suggesting that when physicians and patients disagree about the appropriateness of resuscitation, this is probably due to differences in perception rather than philosophy. Efforts to resolve disagreements should therefore include exploration of differences in perception. Only a tiny minority of patients would request resuscitation if they understood their prognosis to be very poor¹⁶, and others have suggested effective ways to discuss prognosis¹⁹.

Those who acknowledge a poor prognosis but still request full resuscitation may do so because they fear the consequences of a DNR order. While DNR patients felt that a DNR order would emphasize a more "natural" and comfort-oriented plan of care, FC patients felt that a DNR order would lead to passive or suboptimal care, or outright euthanasia. Indeed, some observational studies suggest that orders limiting life support are associated with a higher mortality rate^{20,21}, although other studies have not supported these findings²². Certainly, all health care practitioners have an obligation to ensure that patients with a DNR order continue to receive all other appropriate medical therapies (including life-prolonging therapies) consistent with their goals of care. Physicians who are faced with an apparently illogical request for FC should explore concerns about substandard care.

Although most participants were pleased with their physician's approach to the conversation, many reported a negative emotional response overall. Both FC and DNR patients often reported being shocked or upset by the conversation, either because of the timing or the content, or simply being confronted with their own mortality. Advance Care Planning may help reduce this negative response; by normalizing the subject and raising it before an acute illness, physicians may help reduce anxiety and shock when it is raised during a deterioration^{18,23}. Both FC and DNR patients emphasized the importance of honesty, clarity, and sensitivity when discussing this issue. Previous studies have highlighted the deficiencies of resuscitation conversations^{7,24–26}, and others have proposed techniques to improve them^{11,19,25,27–29}.

Although we deliberately avoided the issues of euthanasia and assisted suicide during the interviews, a number of FC and DNR participants raised these issues on their own. Interestingly, some FC patients associated a DNR order with euthanasia and clearly implied a negative view of the subject, while the DNR patients who raised the issue all supported legalization of euthanasia. Many medically ill patients support euthanasia^{30,31}, but this remains a controversial subject among physicians³². DNR orders are legally and ethically acceptable^{33,34}, and should not be confused or conflated with euthanasia or physician assisted suicide. Physicians who are faced with an apparently illogical request for FC should explore concerns about euthanasia.

Interestingly, no participant reported basing their decision for FC or DNR on the recommendation of their physician, and no participant mentioned a recommendation as either a positive or negative aspect of the discussion. In North America, our current practice favours a model of shared decision-making³⁵ in which physicians are expected to make recommendations based on patient/family values. Although many patients and family members prefer this model², some find these recommendations burdensome³⁶. Our findings may indicate that physicians are not commonly giving recommendations or that these recommendations are subtle enough that they do not stand out for the patient.

Our study has a number of important limitations. Although we attempted to gain an unbiased patient sample by using broad inclusion criteria and enrolling patients admitted consecutively to the medicine service, we excluded patients whom the admitting team felt were emotionally unable to tolerate a resuscitation discussion. This might have eliminated patients who became upset or angry when the team discussed the subject with them, so we may have missed some of the

important patient perspectives that exist in instances of conflict. In addition, we did not interview surrogate decision-makers, whose perspectives and decisions may be different from those of the patient^{17,37}. Based on the results of this study, we might speculate that instances of discordance could reflect differences in perspectives about symptoms, quality of life, goals of care, the stage of illness (early vs. late), the utility of resuscitation, and the relational view of the patient within his/her family. We plan to perform a similar study in surrogate decision-makers in the future.

The study was conducted in Canada, where citizens do not pay directly for health care. Thus, we cannot determine how direct costs of care may influence resuscitation decisions. Some patients in other jurisdictions may opt for a DNR order to avoid causing financial hardship to their family.

When discussing "resuscitation," we did not distinguish between cardiopulmonary resuscitation (e.g., chest compressions, defibrillation) and "life support" (e.g., mechanical ventilation, vasopressors, hemodialysis), but instead relied on the patients to explain their own understanding of resuscitation. We did not attempt to distinguish between the two concepts because previous studies have suggested that patients usually have a poor understanding of resuscitation and life support^{2,8}, and physicians often do not distinguish between the two when discussing resuscitation^{24,38}. Certainly, many of the FC patients in our study clearly expressed a desire for initial resuscitation but not a prolonged course of life support in the ICU.

As with all qualitative studies, our findings may not be generalizable. We studied only English-speaking patients who felt comfortable discussing this issue. Thus, we cannot assume that our findings apply to patients from cultural groups not included in our study.

In conclusion, we learned much about patients' perspectives of conversations about resuscitation. We also identified a number of important differences in the perspectives of DNR and FC patients, particularly in their beliefs about resuscitation and DNR orders, and their reasons for requesting or foregoing resuscitation. We hope that this information can be used to inform educational initiatives for future physicians and help current physicians better understand and address the needs of their patients when discussing resuscitation.

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