

# Shame and Secrecy of Do Not Resuscitate Orders: An Historical Review and Suggestions for the Future

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## Article abstract

This paper clarifies some of the longstanding difficulties in negotiating Do Not Resuscitate Orders by reframing the source of the dilemmas as not residing with either the patient or the physician but with their relationship. The recommendations are low cost and low-tech ways of making major improvements to the care and quality of life of the most ill patients in hospital. With impending physician-assisted death legislation there is an urgency to find more efficient and beneficial ways for clinicians and patients to address resuscitation issues at the bedside. Paradigmatic shifts in the nature of the patient-physician relationship will need to be encouraged by the larger community. These encouraged shifts address the concepts of passive/inferior patient – active/superior physician, patient ownership of and access to all their health care information, and treating the patient as a major participant in the delivery of health care. These recommended changes will not in themselves make any patient, physician or other healthcare provider more humane and open in the patient's final days. The goal, instead, is to have changes to the context of the discussion provide an encouraging environment for more open communication and a balanced relationship among participants with the patient being the most important.

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TÉMOIGNAGE / PERSPECTIVE

# Shame and Secrecy of Do Not Resuscitate Orders: An Historical Review and Suggestions for the Future

John A. O'Connor<sup>a</sup>

## Résumé

Ce manuscrit clarifie certaines des difficultés rencontrées depuis longtemps dans la négociation des ordonnances de non-réanimation en recadrant la source des dilemmes comme ne résidant ni dans le patient ni dans le médecin, mais dans leur relation. Les recommandations sont des moyens peu coûteux et peu technologiques d'apporter des améliorations majeures aux soins et à la qualité de vie des patients les plus malades dans les hôpitaux. Avec la législation imminente sur la mort assistée par un médecin, il est urgent de trouver des moyens plus efficaces et plus bénéfiques pour les cliniciens et les patients d'aborder les questions de réanimation au chevet du patient. Des changements paradigmatiques dans la nature de la relation patient-médecin devront être encouragés par l'ensemble de la communauté. Ces changements concernent les concepts de patient passif/inferieur – médecin actif/supérieur, la propriété du patient et l'accès à toutes les informations relatives à ses soins de santé, et le traitement du patient en tant que participant majeur à la prestation des soins de santé. Ces changements recommandés ne rendront pas en soi le patient, le médecin ou tout autre prestataire de soins de santé plus humain et plus ouvert dans les derniers jours du patient. Cependant, l'objectif est que les changements apportés au contexte de la discussion créent un environnement encourageant une communication plus ouverte et une relation équilibrée entre les participants, le patient étant le plus important.

## Mots-clés

réanimation, soins de fin de vie, relation médecin-patient, mort assistée par un médecin, dossiers médicaux, soins palliatifs

## Abstract

This paper clarifies some of the longstanding difficulties in negotiating Do Not Resuscitate Orders by reframing the source of the dilemmas as not residing with either the patient or the physician but with their relationship. The recommendations are low cost and low-tech ways of making major improvements to the care and quality of life of the most ill patients in hospital. With impending physician-assisted death legislation there is an urgency to find more efficient and beneficial ways for clinicians and patients to address resuscitation issues at the bedside. Paradigmatic shifts in the nature of the patient-physician relationship will need to be encouraged by the larger community. These encouraged shifts address the concepts of passive/inferior patient – active/superior physician, patient ownership of and access to all their health care information, and treating the patient as a major participant in the delivery of health care. These recommended changes will not in themselves make any patient, physician or other healthcare provider more humane and open in the patient's final days. The goal, instead, is to have changes to the context of the discussion provide an encouraging environment for more open communication and a balanced relationship among participants with the patient being the most important.

## Keywords

resuscitation, end of life care, physician-patient relationship, physician assisted death, medical records, palliative care

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## BACKGROUND

The development of Do Not Resuscitate Orders (DNR) Orders in Canada, with their subsequent nuanced name changes, began with the approval of the first “recognized” DNR order in 1979, at McMaster University Medical Centre (now Hamilton Health Sciences) (1). However, unrecognized DNR protocols existed for more than a decade before this.<sup>1</sup>

Efforts to limit resuscitation attempts in hospitals began in secret 1966 at Neasden Hospital, England when the physician superintendent wrote a memorandum to all medical officers and senior nursing staff. “The following patients are not to be resuscitated: Very elderly, over 65 years. Malignant disease. Chronic chest disease. Chronic renal disease. Top of yellow treatment card to be marked N.T.B.R. (i.e., not to be resuscitated) (2).” Four months later, public and political outrage was sparked by a BBC “Tomorrow World” that exposed the existence of the memorandum. Some days after the broadcast, the Minister of Health issued a public announcement stating their Chief Medical Officer wrote to the medical advisory committees of all teaching hospitals:

<sup>1</sup> While writing our DNR policy/procedure, I discovered that two Ontario hospitals already had an active policy. However, when I tried to give them credit for being the first ones, they both denied that they had such a policy.

This advice was that no patient should be excluded from consideration for resuscitation by reason of age or diagnostic classification alone, and without regard to all individual circumstances. Any form of general instruction was wholly unacceptable. The letter added that, as all physicians concerned knew, only a very small number of patients in hospital were affected by cardiac arrest in circumstances in which it would be possible to take measures which could be effective in reversing the process and restarting the action of the heart. Continuing, the letter stated that the nature of the decision to be taken was no different in principle to that required in other grave circumstances, and a decision to operate on a patient or to refrain from intervention might often be of similar importance (2).

European and American governing bodies would basically make no changes to this approach for a decade. *The New England Journal of Medicine* published a set of articles exploring end of life care, including DNR Orders (3-6). The editorial for these articles was titled, "Terminating Life Support: Out of the Closet!"

The hospitals are coming out of the closet! It is an event of the first importance that responsible administrators at two great hospitals — independently, I believe — should promulgate and discuss publicly explicit policies about the deliberate withdrawal or non application of life-prolonging measures.

Ten years after Neasden, limiting resuscitation was still considered a secret. Now, some forty years after the NEJM's articles and despite the plethora of public, professional and academic articles, the issuing of a DNR order still remains "in the closet." All health professional disciplines, clergy of every faith, academics and ethicists of every school of thought have offered solutions. But the DNR Order will not follow its name and settle inconspicuously into the background of broader and more cogent end of life (EOL) discussions.

I have followed and participated in the debates over the years, and to be frank, I did not think any aspect of DNR Orders would be worthy of another journal word. I changed my mind after reading the recent articles by Heyland and others; they concluded in their article:

Medical errors related to communication about EOL treatments are very common in internal medicine wards across Canada, and many older persons in these wards are at risk of receiving inappropriate EOL care. A system-based approach, geared to the relevant needs of individual clinical areas is required to address the communication and documentation failings highlighted in this analysis (7).

This shame-filled secrecy continues, but more sophisticated than the old days of disguised No CPR orders. There are, for example, "Walking Codes", "Slow Codes" (today termed a "Tailored Code" (8)), "Sky Blue Codes", "Show Codes", "Call Me First Codes", "Chest Compressions Only Codes", or an erasable mark on the kardex/patient chart. Even more unusual signs for DNR are flowers on the left or right side of the bed, red dots on the patient's room door (9) (not good in ward rooms), the fantasy of a ledge at the entrance to the chronic care wards, where no crash carts could get over. (This is not good if a staff member arrests.)

These and many other variants continue the tradition of Neasden, where there was no mention of patient consent, or even patient knowledge; the wisdom of the attending physician was the sole determinant of whether a patient received a resuscitation attempt. The most destructive decision, however, was the omission to address resuscitation at all, as if the patient would not die. Let the nurse or resident call a code in the middle of the night, often without them knowing the patient. This concealment theme was resurrected in the modern and quasi-ethical concept of "futility", still as physician-controlled and secretive as the original Neasden policy.

The development of "Power of Attorney for Health Care" and "Living Will" as legal instruments has brought the resuscitation issues to public attention, but in practice seems not to have lessened the conflicts in clinical practice for dying patients and their physicians. The conclusion of a US National Longitudinal Survey reads:

Use of DPOA (Durable Power of Attorney) increased significantly between 2000 and 2012 but was not associated with EOL care decisions. Importantly, there was no growth in ACP (Advanced Care Planning) such as discussions of care preferences. Efforts that bolster communication of EOL care preferences and also incorporate surrogate decision makers are critically needed to ensure receipt of goal-concordant care (10).

## MUCH MORE NEEDS TO BE DONE – NOW

The impact of each advancing technology and drug enables a person to remain alive; but this prolonged living does not necessarily include an improvement in the quality of their lives or prognosis. Dying in hospitals is still far from ideal: palliative care "evidence-confirmed" practices have not been made the required standards of care. So, pain and symptom control, open communication and focus on improving the quality of the patient's living depend on a referral to a specialized and resource-limited service, as if dying is a subspecialty of medicine.

In Canada and many other countries, governments are in the midst of developing legislation and guidelines for Physician Assisted Death. If a society and healthcare system cannot work one of the least important issues of limiting extraordinary interventions in a terminal process, it does not bode well for the more complex decisions in terminating a life. Perhaps we need to make end of life care less conflictual before we attempt the Ending of Life Care.

It is not my intention to single out physicians though they are the prominent protagonists in this shameful conspiracy. We, as patients and as a society, have fed into their needs to be perfect. It is no accident that the patron saint of TV medicine was "Dr. House" who was forgiven all his personal faults and degrading teaching style because he was the best saviour of patients (11). We may not expect our physicians to be Dr. House, though we forgive them almost as often, e.g., after long delays in waiting rooms, we apologize for taking up her time. It wasn't always so. In 1938, a physician remembered a scene from his turn of the century childhood:

The reign of terror during a diphtheria epidemic brings out a trait common to the entire human race; when confronted with unknown perils people seek aid from some Supreme Being. Prayers for protection literally filled the air in those days of doom. There was no appeal to the science of medicine because there was none. The prayers were all abstract supplications; no one prayed that the doctors might find a remedy. No one thought of this possibility (12). The pendulum has swung so far that now everyone expects physicians to find a cure and immediately. Evidenced recently when the media reported that the development of a Zika vaccine was at least 18 months away. The news was full of experts defending this "delay" (13).

## LIKE THE FACEBOOK RELATIONSHIP STATUS: IT'S COMPLICATED

The problem of issuing a DNR Order does not exist because of the characteristics of the patient or even those of the physician. The problem arises and exists because they are in a relationship. Any solution must address the interactions between patient and physician. This is a primary axiom in relationship therapy; the difficulties in the relationship exist because they are in relationship with each other.

Some significant aspects of the physician-patient connection during EOL communication are:

**Changing Goals:** Up until the time when a DNR becomes appropriate to consider, the physician (e.g., oncologists) usually has been the major cheerleader for the patient to stay compliant with disagreeable therapies in spite of the patient's wanting to stop. As well, patients have been listening to their physicians encouraging them not to quit treatment no matter how painful or upsetting. Then, to return to the patient and suggest that they consider a DNR is a personal failure for the physician and the ideals that they have set for themselves (14).

**"You First":** Patients want the physician to raise the issue and physicians believe that the patients should mention it first. Then, both would be willing to talk about it (15).

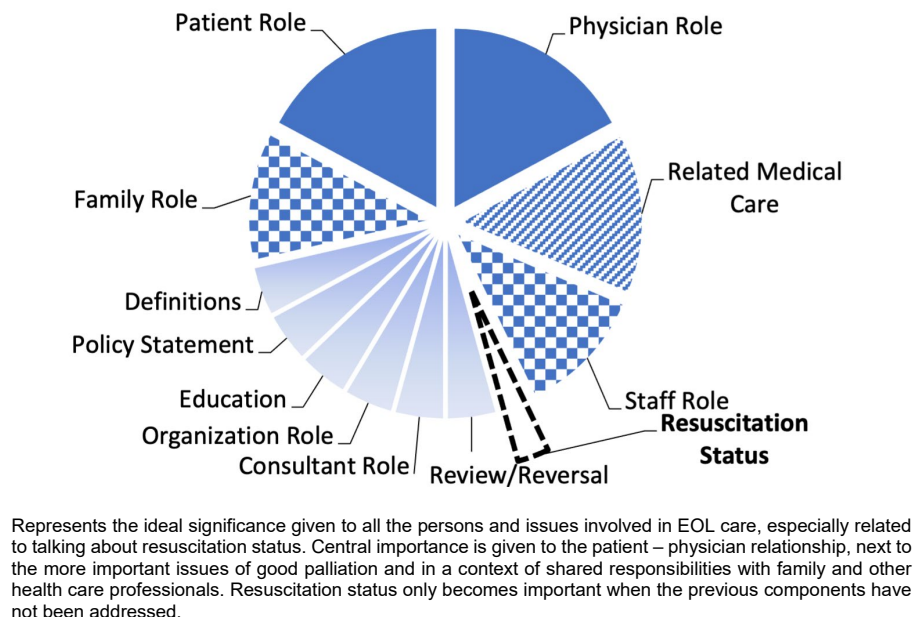
**Language:** Patients speak a language of values and quality; physicians speak of interventions and outcomes. There are gross imbalances of knowledge and power, especially in these days of evidenced-based practice. Values and preferences are significant, but seldom quantifiable. As a result, actual EOL conversation is fraught with difficulties similar to the misunderstandings of "Men are from Mars" variety.

**Knowledge:** Health Professionals are not prophets; they do have the experience to know how diseases usually progress. While a patient sees the same event as just another difficult setback, they have limited awareness of what will unfold. It takes much longer for a patient to become aware of the signs that death is becoming more inevitable.

**Power:** The healthcare system is infused with power politics, with physicians unequivocally with the most; specialists feel more important than generalists; academics feel more significant than practitioners. Other health professionals are left to jockey for the remaining places in the pecking order. How do patients fare in this hierarchy? To read the public relations literature or the consumer rights plaques on walls, one could think that they can have some real influence. Let me ask a question: How many patients will get their competency or decision challenged when they agree with their physician?

**Complex System:** In today's hospitals, a patient does not have one physician; they have a collection of specialists who share their organ/system specific opinions with the patient. "Mr. A, your kidneys are improving remarkably," without reference to the patient's enlarging cancerous lung tumour. These mixed messages from the physicians leave patients confused about overall prognosis.

The issuing of a DNR Order is not confined to the dyadic relationship of patient and physician. It happens in a complex and extensive system. In an earlier paper, we outlined the systemic components necessary to develop a No CPR Policy (16). At the level of writing a specific order to not attempt CPR, the same components need addressing.

**Figure 1. Pieces and Players in the Conversations About Resuscitation**

Any solution must take seriously the characteristics of the patient-physician relationship.

#### **A Solution: Proactive and Forceful**

In “The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment” (SUPPORT) conclusion, we are left with a troubling situation. The picture we describe of the care of seriously ill or dying persons is not attractive. One would certainly prefer to envision that, when confronted with life-threatening illness, the patient and family would be included in discussions, realistic estimates of outcome would be valued, pain would be treated, and dying would not be prolonged. That is still a worthy vision. However, it is not likely to be achieved through an intervention such as that implemented by SUPPORT. Success will require reexamination of our individual and collective commitment to these goals, more creative efforts at shaping the treatment process, and, perhaps, more proactive and forceful attempts at change (17).

Though this direction was prescribed by the SUPPORT Principal Investigators over a decade ago, it seems to have gone unheeded by suggestions to assist compliance with issuing DNR Orders. In a 2015 JAMA Oncology editorial by Dr. Charles Thomas, who was highlighting five articles, he stated:

A communication gap apparently exists between patients and clinicians if the difficult conversations regarding preferred care toward the end of life are not taking place as they should... While creative solutions must be identified via continued research, some solutions may include routine updating of POLST (physician orders for life-sustaining treatment) for each admission, earlier engagement of palliative care teams, and further instruction of communication approaches to ACP (Advanced Care Planning) discussion in the core postgraduate medical education curriculum. (18)

There is a need to promote talks between physicians and patients. I propose just such a proactive and forceful solution. But not by directly dealing with insights for improving the conversation nor will I have ways to better educate physicians or patients. I suggest changing the context of where and how these conversations take place. Attempts to improve the quality of the conversation have not met with improvements in EOL care. My two low cost and indirect strategies to improve EOL discussions are as follows:

First, **return the availability and ownership of the Patient’s Chart to the patient.** Though the name has been changed to “Medical Record”, its purpose has not changed. In the present policy statement, the College of Physicians and Surgeons of Ontario states, “The primary purpose of the medical record is to enable physicians to provide quality health care to their patients. It is a living document that tells the story of the patient and facilitates each encounter they have with health professionals.” (19) At one time, the official hospital medical record was known as the “Patient’s Chart”. It was only euphemistically called that, as the least likely person to ever see it or the information inside was the patient. I would like to bring back the old idea that it is really the patient’s (20-21). I recommend that all hospital medical records be available to the patient, without exceptions. They should be kept in the patient’s room by their bed or available electronically at the bedside. I would extend the right of availability to any person with whom that patient “clearly and unequivocally” wanted to share it. Patients who wanted to do so could read all the information therein: orders, consults and notes. Patients who preferred to say,

“Okay, Doctor” could continue. This has started in a limited way in the US with “Open Notes” (22), however, it requires the patient to ask. I am advocating that this availability be the norm; and the patient could refuse.

Second, Physicians, nurses and other health professionals **give report, handovers, and write orders, consults, progress notes, etc. in the patient’s room or with the patient present**. Several positive changes can be expected. To start with, it would increase the amount of time that all health professionals spend with their patients, and not with their colleagues in a staff bunker. The professionals’ physical locus of work would move back to the patient rather than being limited to moments of necessity brought about by routine rounds or patient call bells. Patients and families would also feel less pressured, more relaxed, and might even have the time to formulate questions before the professional had left the bedside. Informed consent is a process of understanding and not a single event. There needs to be give and take on both sides as to what is being meant by each. Finally, **the writing of comments that the patient and family would see would need to take on a more respectful tone** (23). Such comments as “thanks for referring this grossly obese” or “poor unfortunate” might be lessened. And if the patient/family are going to see the note the professional might want to check with the patient about what they saw as the correctness of the note before posting it.

Some safeguards will need to be built into the process, but these would be supplementary to the essential availability and ownership of the personal health information by the patient. For example, Health professionals might be provided a short period of time before attaching to the chart any reports or results that the physician had not seen. This would allow the professionals time to frame how these results would be interpreted to the patient. There will be different mechanisms for electronic records, but the principles of availability and ownership would be the same (24).

My main recommendations are that first, the prime owner of information about the patient is the patient. In truth, all health professionals are consultants to the patient. Second, a different milieu – one less formal, longer and less pressured (at least for the patient) – increases the possibility of meaningful dialogue among health professionals, patients and their families. These two changes will not force the physician to be more direct with resuscitation and broader end of life decisions. Nor will it remove the experience of shame from the physician. To accomplish this, a bigger shift in nature of the patient – physician relationship will be required. The dance of transference and countertransference, the active – passive nature of the relationship regarding the powers of a physician and patient must be addressed. Consumers see the physician as being more valuable (add any superlative adjective) than they are. Seekers of medical services will need to see physicians more as other contractors, like auto mechanics or kitchen renovators: we need them all to assist us because they have specialized knowledge we do not. Yet, we do not expect our car mechanic to be perfect and solve every problem, especially in some older models. On the other hand, physicians and other professional have a different type of relationship with patients, i.e., a fiduciary one. But is not this now true for almost all specialists with whom we deal? When the car mechanic says you need a part, how many of us could debate that; we take it on trust. Trust is important in all our interactions with specialists; we need to find a new synthesis of the old exclusive dichotomy of contractual and fiduciary relationships.

As Bending pointed out, “The fiduciary model, as applied to the doctor–patient relationship, is paradoxically flawed insofar as it cannot promote the autonomous rights of patients within a fundamentally paternalistic paradigm.” (25) In our contemporary internet world, we receive updates about service due on our cars and a sale on large scallops where we shop. Even more amazing is Google and Facebook who, when I sign on, provide helpful resources on an item I might have desired previously or a new approach to my arthritic knees or a coupon for my upcoming trip to St. Maarten. I am not sure that our physicians are doing the same. Neither the impersonal contractual model nor the “acting on our interests” fiduciary one applies to the present realities.

This shift in being in a relationship with a physician is not to diminish them, but to return them to an “eyeball to eyeball” relationship with their patients. Physicians see themselves as being more fortunate than their patients. They tend to relate from a position of relative strength to a position of relative weakness; mainly they have the power to assist and make better the patient’s life. This works fine until the patient is dying and there is “nothing more” that the physician can do. And the power is reversed: the patient has exposed the imperfect physician (26). So, from relative strength to relative weakness in the face of an incurable patient, the physician is exposed to their distancing shame... of not measuring up. This is the essence of shame.

Western societies have progressed in many areas. Certainly, public and professional discussions about resuscitation and other end of life decisions permeate both the academic and popular press. The next step needed will be to bring these open discussions to the experience of individual patients and physicians in the clinical setting. As the title of the play, “Whose Life Is It Anyway?”, reminds us that the dying person is the primary person (27).

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