End of Life Care

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19.1 Introduction

A do-not-resuscitate (DNR) order is a written medical option that documents a patient's wishes regarding resuscitation and, more specifically, his/her desire to avoid an overtreatment. The DNR order is one of the most important patient care directives that can be issued seeing that it has dramatic and irreversible consequences [1]. ADs are similar and equally important, but include withholding or withdrawing interventions. Resuscitation has the ability to reverse premature death but it can also prolong terminal illness, increase the family's anxiety, and have serious economical consequences [2]. Despite the desire to respect the patient's autonomy, there are many reasons why withholding resuscitation maneuvers may complicate the management of critical illness and perioperative care. Concerns regarding these care directives have been raised by health care workers, patients, and their families. Hence, this explains the need to seriously consider the issues surrounding DNR orders and ADs. The definition of DNR order doesn't change among countries, it is the attitude to deal with it that changes among countries. The objectives of this review will be to describe the different attitudes in various countries regarding these arguments and to present our contribution which focuses on a correct introduction of these issues to future health care provider generations.

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19.2 Epidemiology

Disparities have been ascertained worldwide and also in the United States. DNR orders are, often, stated to the seriously ill but seem to be underused—even among the sickest. More often than not, the diagnosis at admission and the functional impairment are less considered than the age of the patient. DNR orders are frequently stated to older patients, women, and patients with dementia. Furthermore, care directives are stated less often to Afro Americans, patients with Medicaid insurance, as well as those admitted to rural hospitals. DNR orders are significantly higher in private nonprofit hospitals, and also in smaller ones. On the contrary, they are lower in academic hospitals. Standardized rates of the use of DNR orders vary across the states and the highest rates are among patients from rural areas [3, 4]. However, few studies have investigated the role of hospital factors and in particular geographic variations with respects to the use of DNR orders [5].

19.3 Medical Futility, Informed Consent and Informed Assent

The definition and value of the “futility” principle in medical decision making has been extensively discussed and futility is currently being used in clinical practices across the United States and around the world [6]. The new definitions of “medical futility” were developed by a consensus statement of the Society of Critical Care Medicine’s Ethics Committee and can be summarized in Table 19.1 [7, 8]. There is evidence that the process of obtaining “informed consent” may cause considerable distress for patients and families [9–11]. Curtis and Burt [9] contend that to get an “informed assent”—when the patient or family is explicitly invited to defer to the clinicians’ judgment in favor of with holding or withdrawing life-sustaining therapy—is an appropriate, ethical alternative. It is understood that this alternative should not be offered when clinicians are uncertain about the possibility of success or when the clinicians’ convictions about withholding or withdrawing treatment are based on their value judgments regarding the patient’s outcome and quality of life. The ethical property of the assenting process depends on the clinicians’ careful attention to the particular wishes and needs of specific patients and their families. It is equally true that the process of informed consent demands from

Table 19.1 Definitions of “medical futility”

Old definition	Reformulate today
✔ Nonbeneficial	Intervention that is unlikely to:
	✔ Restore
✔ Ineffective	✔ Maintain
✔ Inappropriate	✔ Enhance a life that the patient can be aware of

physicians that they have good communicative skills and that they spend more quality time with patients and their families [9]. An alternative to this is a written "comfort measures only" order. Nevertheless, even if expressed, it is insufficient for redirecting changes in the care of a dying patient. A DNR order is part of advanced directives and many other medical interventions may be withheld upon discussion with the patient or the patient's surrogate. The rationale of a DNR order is not to limit aspects of care, but to avoid overtreatment, and it should not be assumed as a limit for escalation of treatment, i.e. Intensive Care Units (ICU) admission.

19.4 Ethics and Advanced Directives

Around the world, there is still confusion about the meaning of advanced directives and how they have to be followed—the United States, European and Australian health care systems are still working out the details [12]. For a better understanding of the role of various forms of advanced directives, especially DNR order, it is important to consider that the motivating moral idea behind advance directives is similar to that of informed consent. Advance directives are, in essence, a proactive informed refusal of therapies in a future state of incapacity. Informed consent is typically used in the process of obtaining permission to perform interventions (e.g. placing a central line or going through a surgical procedure). Moreover, one of the moral bases for informed consent is to respect the patients' autonomous wishes. This is also true for ADs with respects to the four cardinal ethical points in Table 19.2. In the United States, apart from the living will, there is another autonomous statement of self-determination called the Durable Power of Attorney for Health Care (DPAHC). This statement requires the appointment of a surrogate by the patient according to his/her best understanding of the patient's wishes prior to the onset of his/her incapacity. It is the patient's informed request that determines what is actually best for him/her and can differ from person to person depending on his/her set of values. Without the patient's understanding of where his/her interest lies, a physician cannot know how to provide benefit or avoid harm to him/her. In the absence of an AD or proxy decision-maker, the general preference is to preserve life when possible. European authorities, on the contrary, after decades of debate favouring paternalism, have

Table 19.2 To solve every clinical dilemma: the four cardinal ethical points

Autonomy	The right of the patient to accept or refuse any treatment
Not malefiency	Doing no harm or, even more appropriate, no further harm
Beneficial	Implies that healthcare providers must provide benefits in the best interest of the individual patient while balancing benefit and risks
Justice	Implies the concern and duty to distribute limited health resources equally within a society, and the decision of who gets what treatment (fairness and equality)

Table 19.3 EU Institutions referring values and operating principles

Values	Principles
✔ Universality	✔ Quality
✔ Access to good quality care	✔ Safety
✔ Equity	✔ Care based on ethics
✔ Solidarity	✔ Patient involvement
	✔ Privacy
	✔ Confidentiality

now fully endorsed the ethical principle of autonomy [12]. Still, even though the legitimacy of surrogates is now recognized by physicians, new legislations emphasize the patients' autonomy all over Europe. These conclusions were evidenced by the values and operating principles recognized by the Council of the European Union in Table 19.3. In Australia, patients are allowed to plan in advance the medical treatments in the event of incapacity through the use of ADs. Such a policy is verified in jurisdictions where the statute ADs qualifying or actioning scope are prescriptive enough for organisations to expect all health professionals to appropriately observe them. Differences in ADs frameworks across Australian states and territories are still unclear and therefore, health professionals are in need of a policy to determine their expected response. ADs are frequently discussed and considered during stressful and urgent circumstances in Emergency Rooms (ER) and in (ICU). It is well-known that in emergency situations it is always difficult to verify the presence of a DNR order, and subsequently to make a quick decision while taking into consideration the family's presence on the scene [13]. For this reason, discussions about DNR orders and ADs should be essential part of the standard for continuing well-patient care even for all competent patients. The patient/physician dialogue ought to continue even after patients have filled-out any forms, allowing the patient to develop an overall view regarding future medical care and give them the possibility to change their minds over time.

19.5 Patients' and Physicians' Attitudes Towards the Discussion of DNR Orders

In the United States, physicians' attitude to discuss this issue is on the rise. An open dialogue should take place between each patient and nurse or physician, not only when the patient is in proximity of death but even before. This dialogue aims to express the values that could help guide a decision-making process when the patient is unable to make his/her own decisions. In addition to this, a patient can choose a family covenant- an open health care agreement that can facilitate advance care planning. The family covenant provides a framework for the patient, his/her family, and the physician in an interactive dialogue. Since individual values are the relevant features of an AD, making those values clear and explicit can greatly assist the family and the physicians to achieve the patient's benefit. It is also necessary to identify how nurses and physicians perceive end-of-life care so that their communication can be improved [14]. Even today, physicians are more likely to discuss DNR orders only when the patient's prognosis is poor. It has been noted that despite the short surviving time of cancer patients, many have never signed an AD. This may be an indicator of suboptimal doctor/patient communication [15]. A full consensus still hasn't been given with regards to DNR order terminology. For instance, some authors argue that the term "do not resuscitate" (DNR) is ambiguous and should be replaced by "allow natural death" (AND) [16].

19.6 Legal Aspects of the DNR Order

In the past, legal precedents and ethical interpretations dictated that patients were expected to receive full resuscitation unless there was explicit documentation expressing the contrary [17]. The decision "not to resuscitate" was first legalized after the mid-1970s. In the USA the American Medical Association first recommended that decisions to forego resuscitation be formally documented. Furthermore, it was emphasized that Cardiopulmonary resuscitation (CPR) was intended for the prevention of a sudden, unexpected death—not the treatment of a terminal, irreversible illness [17]. Explicit DNR policies soon followed, and the patients' right to self-determination was promoted. The event that prompted the enactment of the Patient Self-Determination Act was the Cruzan case which involved a young woman who was left in a persistent vegetative state after being resuscitated from a cardiac arrest following a car accident. Her parents and husband went to Court against the state of Missouri to demand the removal of her life-support system. The case ended up in the Supreme Court who sided with the State of Missouri agreeing that the State had the right to require "clear and convincing evidence" that Nancy Cruzan would have wanted life-support terminated. Nevertheless, the Supreme Court upheld the legal standard that competent persons are able to exercise the right to refuse medical treatment. Only after the family found such "clear and convincing evidence", was Nancy Cruzan removed from life-support almost 12 years after her persistent vegetative state. Until the Cruzan case (1990), there had never been any law about the clarity DNR orders and ADs. After this precedent, the Patient Self-Determination Act (PSDA) went into effect in 1990, making ADs legally acceptable by statute in all 50 states. During the Cruzan case, the Justice emphasized the importance of clear oral and written instructions prior to incapacity, as well as a clear appointment of durable powers of attorney, as the means for an incompetent individual to exercise his/her choice. The PSDA of 1990 is now responsible for the reduction of the number of patents without written ADs [18]. The DNR issue was considered not only in out-patient clinics but in perioperative time too. After the 1990s, decisions were typically left to the attending surgeon and/or anesthesiologist, and DNR orders were routinely suspended during the intraoperative and immediate postoperative periods. In 1991, several articles criticized this widespread practice [19]. In effect, concerns were raised that patients were forced to compromise their autonomy and right to self-determination in order to qualify for surgery. This led to a policy of 'required reconsideration'. The American Society of Anesthesiologists formalized this policy in a set of guidelines approved in 1993 and updated in 1998 [20].

19.7 Advances in Future Perspectives

There is evidence of several different DNR order polices throughout the world (Table 19.4) and the lack of a universal DNR order policy. In all countries, need of standardization appears clear and below are several contributions support the target for achieving a consensus in this critical issue [21].

19.7.1 Increase Communication

A good open dialogue is essential between patients, families, religious representatives, and hospital staff in order to clarify the patient's preferences if he/she is still mentally competent. A formal education directed towards physicians is urgently needed to improve the frequency, quality, and timing of discussions concerning DNR orders and ADs in undergraduate and postgraduate curricula in medical and nursing schools.

19.7.2 Code Status Discussions

The DNR order is the only order that requires patient consent to prevent a medical procedure from being performed; therefore, informed code status discussions between physicians and patients are especially important. It is challenging to find specific strategies that can improve the quality of code status conversations and enhance end-of-life care planning, but there are no guidelines for code status as of yet.

19.7.3 Consensus on Law

Today, advanced directives are a debated issue all over the world. In the future, it will be necessary to achieve a consensus on law. The challenge is to find common traits in the different beliefs and religions to gain a standard policy.

Table 19.4 DNR order around the world

Country	Policy
USA	Signed consent policy Witnessed verbal consent policy
South America	Oral orders take preference ADs: physician thinks to share with the patient in decision making
UK	An advance refusal has legal force
Spain	DNR decisions are clearly indicated to limit the therapeutic effort
France	Directives by the patient's family or a surrogate decision maker have only a consultative role Care decisions are made after a collegial procedure
Belgium	Law regulating euthanasia End of life decisions often occur within the context of multidisciplinary care
Norway	Withholding and/or withdrawing life-sustaining treatment were taken in the aftermath of a DNR order
Netherlands	Euthanasia and self-written ADs are legally binding
Italy	Guidelines (SIAARTI) but there is not a law The doctors decide what to do trying to respect and giving a right interpretation of patient's will
Israel	No consensual practice Strong ethnic and religious beliefs (e.g. Jewish religion considers the dying event as an uninterrupted, peaceful transition from life to death)
China	It is preferable that dying people exhale their last breath at home More DNR orders being written
Japan	The physicians could institute DNR order without consulting the family when the physician feels that a CPR is unjustified and futile (The Japan Society for Dying with Dignity)
Australia and New Zeeland	Most of patients prefer DNR orders to 'good palliative care' orders and prefer written orders

19.7.4 Increase Trust Among Patients, Physicians and Health Care Systems

Physicians should educate terminally ill patients with regards to their wishes concerning life sustaining treatment and provide psychosocial support so that patients feel comfortable about expressing their preferences. Avoiding futile interventions [6] (Table 19.1) would be an important step to increase trust between patients and healthcare systems.

19.7.5 Improve Standards and Quality of Care

In authorizing a DNR order, surrogates must face a strong emotional experience. Signing a DNR order is a process and not an isolated act. Good quality communication and psychological support from health care staff are very important. 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 when signing the DNR order.

Moreover, there is evidence that ADs (living wills) are associated with end-of-life expenditures and treatments. This results in significantly lower levels of Medicare spending [22]. To improve standards of care, it is important to consider the current guidelines for example, the AHA guidelines state that: "Out-of-hospital DNAR protocols must be clearly written and easily implemented for all persons involved (members of the healthcare team, patients, family members, and loved ones). DNAR documentation can take many forms (e.g., written bedside orders, wallet identification cards, identification bracelets, or predefined paper documents approved by the local emergency medical services [EMS] authority). The ideal out-of-hospital DNAR documentation is portable and can be carried on the person" [23]; even the ERC guidelines are useful for the orientation of healthcare providers [24]. However, what is stated in the guidelines is "suggested" and the way to carry it out depends on the different cultures and beliefs.

19.7.6 To Respect the Patient's Will and the Family's Role

The DNR order reflects the patient's desire after full cardiopulmonary arrest. Correct interpretation of living wills and DNR orders is essential if patient safety and autonomy are to be preserved. The living will is an expression of informed consent or refusal before the patient becomes terminally ill (or persistently vegetative) and/or has lost his/her decision-making capacity. The patient's benefit is at the ethical center of advance directives, and his/her wishes are crucial for understanding what is best for him/her. The family is often involved in the decision-making of the critically ill (Fig. 19.1). Family dynamics and medical/legal concerns most often affect decisions to obtain/write a DNR order for critically ill

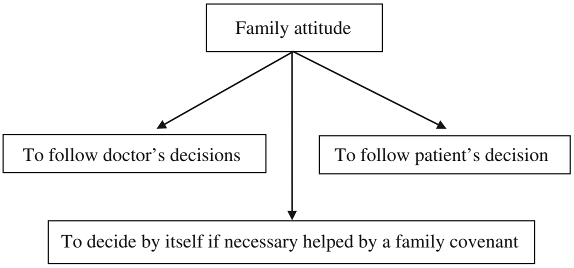

Fig. 19.1 Family attitude in case of end of life care

patients. Complicated situations may occur when family members do not support the goals of care determined by the patients. In this case a figure such as a family health-care provider or a family covenant can be helpful to mitigate conflicts.

19.7.7 Continue Education on Professionalism

Ethical values in clinical practice, especially patient autonomy, should be addressed during the early stage of the medical curriculum. The education, scholarship and ethical values of the Medical Professionalism proclaims concepts such as: maintenance of competence, ethical behaviour, integrity, honesty, relationship, responsibility, accountability, service to others, adherence to professional codes, justice, caring, compassion and altruism but also include respect for others and self regulation [24, 25]. This means that what should be taken into consideration is the patient's will and not what physicians think is "better".

19.8 Conclusion

After these considerations, it is clear that a serious professional reflection is absolutely necessary concerning end-of-life care. Despite the ardent desire to sustain life, medical professionals should withstand the temptation to act when the patient's wish is to not be resuscitated. Rather than perceiving that they are *doing nothing*, something has indeed *been done*: the patients' wishes have been respected, their autonomy has been preserved and they have been allowed to die with dignity. Unfortunately, complying with these wishes still represents a real challenge for patients and their families, physicians, nurses, as well as the society.

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