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# **Family-Centered Care to Improve Family Consent for Organ Donation**

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Additional information is available at the end of the chapter

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## **Abstract**

The need for organ donation has increased over time, but the shortage of available donors is the major limiting factor in transplantation. Organ donation refusal from relatives of potential donors with brain death significantly reduces organ availability. We report a brief analysis about family conflicts in decision-making and causes for refusing donation; moreover, we describe new family-centered strategies in the intensive care unit (ICU) and our systematic communication approach between medical staff and patients' relatives. In 2016 we conducted a single-center, non-randomized, controlled and before and after study in our ICU, an 18-bed intensive care unit (ICU) of a university hospital. We compared the rate of consent for organ donation before and after the introduction of the new communication approach. The application of a new communication approach between medical staff and relatives of brain-dead patients was associated with a significant increase in the rate of consent to donation. The positive results of the 3-year period 2013–2015 have been confirmed in the 2-year period 2016–2017. Our results highlight the importance of empathy and counselor support of relatives in the ICU.

**Keywords:** organ donation, patient-centered care, intensive care, family

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## **1. Introduction**

The number of donors is inadequate although the need of organ transplant has increased over recent decades [1–4]. Most of the organs available for transplantation come from deceased

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rather than living donors. Then, patients who have been declared brain death are the largest source of transplantable organs. The consensus rate improvement of solid organ donation from deceased donors is considered one of the main strategies to increase the availability of organs for transplantation. Unfortunately, a low percentage of people register their donation wishes in life. Furthermore the laws concerning individual consent expressed previously in life are dissimilar in different countries; above all, the population's adhesion to the law may not be comparable so that family members are often the only ones that can express consent to organ donation. Although the main factor limiting the number of donations from brain-dead potential donors is the low rate of consent from their families. Furthermore, in the clinical practice, even when the patient has registered their will on the organ donors' registry and there is no legal obligation to obtain consent from the relatives, if a relative denies the consent, organ donation may not proceed [5, 6]. The consensus rate improvement of solid organ donation from deceased donors is considered one of the main strategies to increase the availability of organs for transplantation. They get the bad news about the possibility and then of their loved one's death in a short time. The settings where family members receive this information are intensive care or emergency areas, unfamiliar, unknown and often confusing places. Several studies examined the reason why some potential donors' families refuse consent, while the others analyzed a series of "modifiable" factors related to meeting with the family(s) especially. Kerri Barber et al. in 2006 reported the results of an interesting audit of all deaths in intensive care units (ICUs) from 1 April 2003 to 31 March 2005 regarding 341 intensive care units in 284 hospitals in the United Kingdom [7].

Among the relatives of 2320 potential heart-beating donors who were approached for donation consent, 41% refused. The main reason for refusal is the knowledge of the desire not to donate expressed by the deceased person in life (16%). In the last 20 years different studies have emphasized how privacy and request timing, the involvement in the patient care team that gives information to the family of at least one member of the staff of organ procurement and a care to brain death significance explanation are key factors to improve relationships [8–10]. Furthermore several authors pointed out that religious, cultural and social beliefs play an important role in the family's decision-making process. Besides, concerns on exact time of death and body integrity after death and emotional vulnerability are equally crucial. The process is also influenced by education, income, sex and age of the family members [6, 7, 9, 10]. There are many relationship elements and emotions involved in the donation process. Ignoring family's emotions without taking care of the relational aspects can hamper fully aware choices. De Groot and colleagues in 2015 reported the results of a qualitative research in a group of donors' relatives regarding the decision-making donation process. We reported the main results of this research in this context. The authors confirm how the stressful sudden event, the interaction with unknown people, the difficulty of mourning and making a decision for the loved one whose loss is being wept over are determinant factors in the decision-making process of the family. The occurrence rapidity does not allow us to be aware of the reality we are experiencing and of any decisions that must, in any case, be taken. The potential donors' relatives describe the decision-making process as complex mainly because they had to make a decision on behalf of the deceased (surrogate decision). The conditions that might contribute to this complexity are the feeling of having limited time and

a sense of urgency, the feeling of not being competent to decide and a sense of despair and crisis and the need for an agreement between all relatives. The ethical considerations regarding the possibility of helping others, the integrity of the body and life after death reveal the emotions and personal motivations coming into play going beyond the event itself and the immediate and concrete decisions that family members are called to take [11]. Vincent A et al. also reported the common reasons for family refusal: relatives not wishing surgery to the body (concerns regarding disfigurement), feelings that the patient has suffered enough, feeling incompetent regarding the patient's wishes, disagreements among the family group, religious/cultural reasons, dissatisfaction with the health-care staff and process, concerns over delay to the funeral/burial process, inability to accept death, lack of understanding of brain death, concerns regarding integrity of process and the fact that they were emotionally exhausted themselves.

The same authors pointed out that several studies come to the conclusion that following elements could be useful [12]:

1. Guaranteeing the right timing of a request
2. Guaranteeing an appropriate setting
3. Providing emotional support
4. Imparting specific information (e.g. regarding the nature of brain death)
5. Guaranteeing adequate staff training
6. Guaranteeing staff involvement in a planned process of the organ donation request

Italy as a whole is undoubtedly the country that has developed a model similar to the Spanish one. Spain has become a reference point for European and global solid organs donation and transplantation with the highest donation rates. Italy has a cultural and health structure similar to Spain and it is needed to create an organizational structure since the 1999 law [13, 14]. In 1988, the Council of Europe Committee of Experts on Transplantation (SP-CTO) was established. The Committee included more than 30 countries with observatories from Canada, Japan and Israel and was incorporated by the Eastern countries for which it represented the only contact with the great Western countries' transplant referents for many years. The Organización Nacional de Trasplantes (ONT) held the presidency of this Committee for 7 years (1995–2000 and 2003–2005). The majority of the documents you need as a basis for the preparation of the Commission and the European Parliament actions on transplants have been processed in Spain. Following the approval of Article 157 of the Amsterdam Treaty, the European Union has developed the European directives on transplantation, guaranteeing the quality and safety of the tissue and cell organs. In May 2003, the Executive Council of the World Health Organization (WHO) accepted to set up an international group of experts to examine the issues related to transplants, including xenotransplantation. Spain is the promoter of a punctual organization in the field of transplants that Italy has been sharing. In particular, Italy shares with Spain the following key points regarding transplantation.

- The health status of a country or region is also affected by a good functioning of the donation transplantation system. This is conditioned and conditions a good quality health system
- A training program is needed for intensive care and operating theaters' doctors who work with potential and receiving donors

Spain has collaborated very actively organizing different types of courses some of which specifically concern family members' interviews. The proximity between Italy and Spain and the similarity of the language facilitate the collaboration process between the two countries. Italy currently has a three-level (national, regional and hospital) transplant system organization and a training system that follows the Spanish model. Initially, the percentage of refusal to donate was quite high; currently, the percentage of waste is about 30% and it has been stable for some years. We believe we can still do a lot to reduce this waste amount. The WHO provides technical support for the correct development in the field of transplants, promotes international cooperation and continues the examination and collection of global data on allogeneic transplantation safety, quality, efficacy and ethics.

The work strategy adopted to implement donations is based on a process called global base of knowledge about transplant (GKT) defined in resolution WHA57.18. The GKT consists of four lines of work that require progressive development and includes the following aspects:

- GKT1: It includes activities and practices in allogeneic transplants.
- GKT2: It includes allogeneic transplants legislation and organizational systems. The main objective of the registry is to gather information on organs, tissues and cell donation and transplantation activities, as well as information on the legislative and organizational aspects of transplantation all over the world and to make professionals and the general public know them.
- GKT3: It includes response to transplants, risks, survival and surveillance systems, safety aspects and ethical aspects. Creating systems is considered a surveillance priority that guarantees transplants safety, so that any effects and adverse reactions, both in receiving and in living donors, can be communicated to take any necessary measures. From an ethical point of view, it is intended to obtain information on the measures taken from member states to protect the poorest and most vulnerable groups, for example, from organ and tissue trade.
- GKT4: It includes xenotransplantation. Xenotransplantation could be the alternative to the lack of human origin organs and tissues. However, experimental preclinical tests haven't justified human clinical trials yet. Transparency is a fundamental and mandatory requirement for the WHO in donation and transplantation-related practices, as well as in information collected around the world.

To find out more about the world situation regarding organ transplants, we recommend the website [2].

No religious beliefs preclude organ donation; people usually refer to personal conscience. The national frame guarantees quality and safety for the donor and the receiver [15].



With regard to all that was mentioned above, we believe that optimizing the relationship with the potential donors' relatives might represent the main organ procurement strategy. The intensive care setting is the place where this relationship can be created.

The past two decades witnessed an increasing interest in the importance of health-care humanization. The recent guidelines suggest organized interventions and approaches aimed at supporting the families of critical patients. The objectives are twofold: to reduce the impact of serious illness and to prepare family members for decision-making and assistance needs. An international consensus recognized a new definition: "family" and "family-centered care" to identify this approach. The term "family" intends to identify a group of individuals who support the patient and with whom the patient has a significant relationship. "Family-centered care" is a respectful and responsive approach to health-care that meets the needs and values of individual families and is mainly characterized by: family presence in the ICU, family support and communication with family members. Family members will not only be present within the ICU but also actively participate in the care process. It is recommended that validated tools exist to optimize communication quality, medical understanding and reduce family decision-making conflicts, in setting the ICU up. Care practitioners must apply standardized and agreed communication approaches with family members of deceased patients and above all for those who died with brain-death criteria, especially [16]. Seaman J.B. and colleagues in *Annals ATS* (2017) suggest that the goals of clinician-family communication should be diversified and concern different aspects [17]. We very much share the elements discussed by these authors and we comment on some of them that seem relevant and in line with our choices. First of all, it is about establishing trust. The most important element of the quality of care for seriously ill patients' family members is the condition of trust in the care team. Sharing the decision-making process requires trust in the care team and at the same time allows to achieve a more stable relationship with the family members. Because family members can decide (when they are called on to do so) they must understand what has happened (and what the clinical consequences are), the effect of the choices on the beloved and the risks and benefits of the shared pathway. The second one is providing emotional support. ICU patients' family members have high levels of emotional stress and experience intense negative emotions such as fear and anxiety. These feelings are exacerbated by the communication of the bad news (death or threat of death) and by the decision-making process itself. Research in the neuropsychological field suggests that strong negative emotions such as fear and anxiety do not allow processing information detaching the subject from the reality (as already mentioned above). Therefore, attention to the relationship also allows us to devote a time to recognize emotions and reflect on them. Third element is conveying clinical information. Clinicians should take into account that family members should be informed in a clear, simple and precise manner regarding the diagnosis, prognosis and possibilities of patient treatment. Families need to be involved in the decision-making process. Lack of correct information can lead family members not to take the right decisions for the patient as well as being a source of stress and frustration. The authors confirm the importance of the interdisciplinary team role (involving psychologists, social workers, volunteers, care coordinators and communication facilitator) to improve family satisfaction and decrease psychological symptoms.

## 2. Our experience and discussion

### 2.1. New communication approach

Since 2013, as we have recently published, we developed a new communication approach addressed to relatives of patients admitted to the intensive care unit (ICU) ([18], with permission). It consists of a patient/relative-centered approach, in which doctors, nurses, psychologists and volunteers support relatives throughout the care process. First, they try to acquire information on the family's social and cultural background and adjust the communication accordingly and second, they aim to understand the patient's will, a task that can be challenging in the intensive care context. When the patient first enters the ICU, the physician must give priority to treatment and can only speak briefly to the relatives. He reassures them that there will soon be time to acquire information and ask questions. As soon as the patient's conditions allow an interview with the relatives is performed so as to establish a relationship between the physician and the family. The physician who followed the patient's acute phase, the nurse who is in charge of him or her and a psychotherapist or a psychologist conducts it in a dedicated room. The staff also takes note of the relatives' phone numbers. The following interviews take place in the patient's room. During the first interview, the medical staff harmonizes on the needs and feelings of the family and retraces the patient's history and the recent acute event. This interview also aims to identify the main caregivers and establish the timetable and program for the following days. We applied a well-defined model, which can be divided into several steps:

1. Giving a warm welcome to the patient and his family unit;
2. Identification of the caregiver among the family members;
3. Taking care of the patient and relatives in a multidisciplinary way;
4. Early involvement of a psychotherapist;
5. Communication to the family in the patient's room;
6. Giving information on the patients' clinical conditions by the physician, the nurse and in presence of a psychotherapist and a volunteer;
7. Communication between the family and the psychotherapist and volunteer, with special regard to the family members' emotions and feelings.

### 2.2. Relationship with donors' families

The changes in the interaction modalities with family members and with the patient, when possible, have been consolidated since 2013 in our ICU; the changes represented a structured intervention. We believe that the new relationship's modalities with the patients' relatives, so far exposed and described in their reliability, have favorably influenced the reduction of opposition to organ donation by the family members of the deceased patient. Our ICU is an 18-bed, multidisciplinary ICU. It is a referral center for acute respiratory failure as well as a

trauma center. Relatives of brain-dead patients were approached according to an internal protocol, inspired by NICE guidelines, which temporarily distinguishes two phases: communicating brain death and proposing organ donation. These guidelines deal with delivering the end-of-life communication and developing a supportive relationship with potential beating-heart donors' families [19]. Often, patients who develop brain death did not express their opinion on organ donation during their lifetime. In our ICU all patients and relatives including relatives of brain-dead patients have been approached by the medical staff to establish a relationship since 2013, aiming at making them feel better and understood. The number of acceptances to organ donation in our intensive care was observed before and after the implementation of two major interventions: the opening of the intensive care (project called "OpenICU") to relatives and the introduction of the innovative communication approach mentioned above. Opening ICUs should come about not so much in answer to pressure generated by a growing social awareness, or in simple recognition of a right, but because this policy addresses more comprehensively the issue of respect for the patient, as well as providing more appropriate responses to many needs of both patients and families. It is a decision which requires doctors and nurses to rethink their relationships with patients and their families, which calls for original solutions for each individual situation and which should be subject to periodic checks. Psychotherapists support the relatives in finding a meaning to their experience and to understanding their own reaction and attitude. Further elements could have positively influenced the decline in organ donation, such as:

1. Increased attention to the initial welcome to the patient and his family;
2. The creation of a multidisciplinary team, giving a new value to non-medical figures, such as psychologists and volunteers;
3. The enhancement of giving information in the patient's room.

The Open ICU is realized when the whole team aims to abolish all of the unnecessary limitations at a temporal, physical and relational level. Opening the ward to family members allows patients and their relatives to be actively involved, fueling the healing process through affection and contact with their beloved. Besides, it helps patients to better tolerate hospitalization. When the Open ICU first opened, an innovative concept was introduced: interview with relatives no longer took place in a separate and impersonal "medical staff room." It was moved into the patients' room. This gave the opportunity for relatives to be physically close to their beloved while receiving bad news. This physical nearness soothes the relatives' grief. Being in the patients' room means sharing the environment with him or her: they hear the same sounds, feel the same temperature and see the same colors. The patient, his family and the physician now share the same scene. The relationship is still asymmetrical as the physician decides what to do and is trusted. However, the patient and his family are now considered as central elements of the scene. In fact, during the interview, there is an exchange of information between the physician and the family; the former is open to questions and doubts expressed by relatives, reducing errors related to a subjective interpretation of reality. Rather than speaking to the patient's family, the physician speaks with the patient's family. Conducting the interview in the patient's room also facilitates questions on machines and therapies with



which relatives are not familiar. Apart from verbal expressions, body language (which comprehends movements toward or from the patient, facial expressions, position of the relatives in the room) is part of the relationship between physician/nurse and the patient's family. In this regard, the interview taking place in the patient's room recalls the historical role of the doctor, who visited patients at home. Just as in the past, the doctor moves toward the patient. This movement is symbolically meaningful in the relationship. We think it is also important to recognize the emotions of both the family and the physician, who are all involved by seeing the patient while the interview takes place. The physician, the patient and the relatives recreate a family unit, giving more humanity to a very difficult moment that involves communication of the ICU patient's condition.

Besides, there are a few gimmicks that help improve the family's comprehension and memorization of information:

1. Communicate one piece of information at a time, in a specific, accurate and coherent way, "need to be honest, but should aim to mitigate the stress rather than exacerbating the fear and uncertainty";
2. Explain the patient's priorities in that moment;
3. Invite the family member to ask questions;
4. Verify that family members have understood what is explained to them.

The interview with relatives has several functions: it is informative, it is clarifying and it contains the family's emotional reactions. This last one is paramount in an ICU, where patients' deaths or losses of functional capacities can take place unpredictably. Historically, trust in doctors has been an unconditional feeling. During emergencies and critical events, families have no choice but to trust physicians, who are in charge of their relative's lives. Nevertheless, this trust must be respected and preserved because it is no longer unconditional. Nowadays, it is based on the physician's empathy with the relatives' emotions and on giving explanations to their worries and questions. By taking the family's emotions in charge, the physician creates a trustworthy relationship with them and can then make realistic predictions of survival and prognosis with them, also facing the topic of terminal illness. Many patients experience anxiety because of hospitalization and the impending threat to their lives. Similarly, psychotherapists help relatives to decrease their level of anxiety, allowing them to experience the ward as a more "human place," where there is space for relationships with the caregivers, who respond to help requests and throughout which emotions can be shared. The physician respectfully listens to the patient's or relatives' worries, allowing them to elaborate their emotions. At the same time, the physician conveys clear information authoritatively, though in a sensitive and truthful way. This is identified by Castagna as a counseling relationship, through which individuals develop awareness of their experiences and needs. Thanks to such relationship, patients manage to handle a challenging moment of their life by expanding their inner strength, even when reduced by critical illness. By communicating, we improve our shared knowledge, the so-called "common sense," the essential precondition to the existence of a community. Among the multidisciplinary team, a special

mention must be addressed to nurses. Nurses are probably the health-care professionals who spend more time with patients. Because of the Open ICU, they often work while relatives are in the room and most of the time not in the presence of physicians. For these reasons, they are in charge of explaining to the relatives what physicians told them during the interview. Their relationship with the patient and with relatives is unique and contributes meaningfully to the care-taking process. Even though they are not professionals, volunteers act as a connection between the world outside the hospital and the ICU. When nurses and physicians are occupied in emergencies or in routine clinical activity, relatives find an important referral in volunteers.

Potential donor patients' family members receive a favorable impact from the host, support and relationship strategies described so far. When brain death is declared, the family is entrusted by the care team to a dedicated team of the organ procurement. Relatives of brain-dead patients were approached according to an internal protocol, inspired by NICE guidelines, which temporarily distinguishes two phases: communicating brain death and proposing organ donation. These guidelines deal with delivering the end-of-life communication and developing a supportive relationship with potential heart-beating donor families.

The end-of-life communication recognized the following seven details:

**Suggested locations:** doctor's office, conference room, relatives meeting room, no hallways and common areas.

**Meeting participants:** intensive care specialist in charge of the decedent's care, nurse appointed to provide specific support, physician and nurse in charge of the transplant coordination system, family members wishing to be informed and psychotherapist. It is crucial that both staffs are present during this phase: the medical staff in charge of the patient, which will introduce the transplant coordination system staff.

**Environment arrangements:** sitting in a circle, if possible, access to phone calls, paper handkerchiefs, glasses and water. Avoid placing writing desks between the speakers and the relatives. Do not behave/act with detachment or indifference: avoid folded arms, fisting and fiddling; do not look away from the interlocutor; do not speak in a formal or distant way.

**Delivering the communication (how and when):** only after the first observation to assess the patient's death according to the Italian legislation. The assessment declaration is clearly and simply formulated by the intensive care specialist: "The EEG tracing we've just performed reveals the absence of brain electrical activity, there are no reactions to external stimulation, and the patient is not able to breathe autonomously. These circumstances unfortunately describe a death diagnosis. The legal-medical procedure to assess brain death has just started, and it will go on for 6 hours. At the end of the 6 hours, we will stop the artificial respiration procedure that is now keeping the heartbeating." A summary of the patient's clinical and therapeutic history can be added. Verify that relatives understand the meaning of brain death.

**Developing a supportive relationship:** give the family the appropriate time to react to the communication. Do not try to control or limit their reaction. Let them express rejection, denial, incredulity, anger, violent anger, desperation and so forth.

**Medical personnel cope with reactions caused by the end-of-life communication:** keep a silent and empathic behavior. Take care of actual necessities such as drinking, making telephone calls and handkerchiefs. Listen empathically to the relatives' memories on the patient's life and on the history of the illness that caused his death (accident dynamics, health-care delays, diagnosis mistakes, disappointed expectations on surgery and treatments, family problems, and so forth). Do not make obvious or inappropriate statements such as: "I'm so sorry for you," "I can understand your pain," "I know you're angry and I understand this," and so forth.

**Visiting the bed:** the nurse was appointed to support the family or the transplant nurse coordinator introduced themselves and their job. They take the relatives wishing to visit the patient to the patient's bed. Group visits are allowed (according to the size of the patient's room), preferably after the first reactions to the communication of death. The nurse answers to every question about heartbeat after death in a simple way: ".heartbeats and blood pressure are still being monitored because the heart is beating. We are sending oxygen to the heart artificially with a ventilator that is pumping air into the lungs but, unfortunately, there is no brain activity. The patient is not able to breathe autonomously and his chest is still moving just because of the ventilator." The nurse can offer the assistance of a religious person to administer the last rites and pray with the family.

A donation proposal recognized a following four details:

**Suggested location:** doctor's office, conference room, relatives' meeting room, no hallways and common areas.

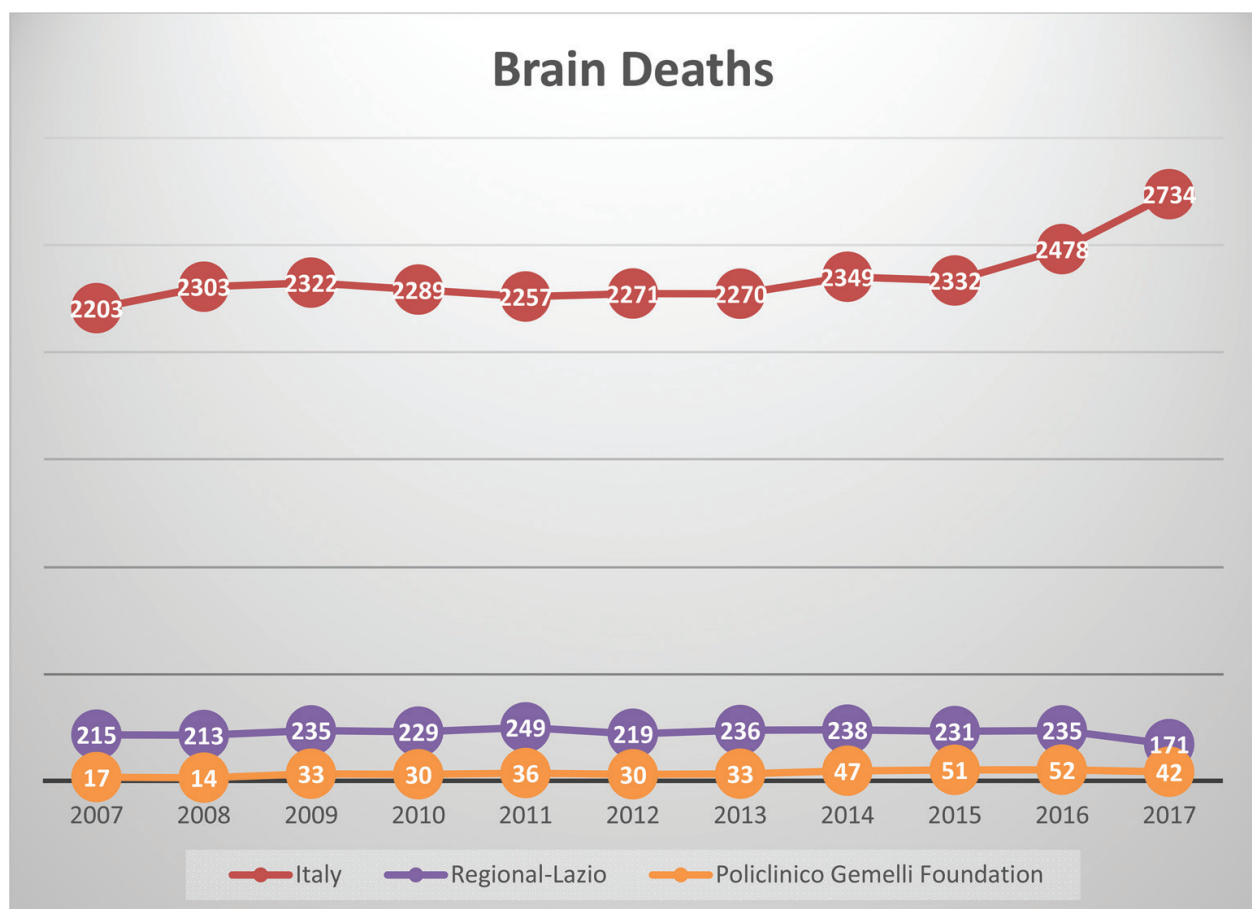
**Participants:** intensive care specialist in charge of the patient's care, nurse appointed to provide specific support, physician and nurse in charge of the transplant coordination system, family members wishing to be informed and psychotherapist.

**Environment arrangements:** sitting in a circle, if possible, access to phone calls, paper handkerchiefs, glasses and water. Avoid placing writing desks between the speakers and the relatives.

**Delivering the communication (how and when):** The organ and/or tissue donation proposal follows in all cases the death communication, the bed visit and the last farewell. Before the donation proposal, it is advisable to give a brief summary of the patient's clinical conditions, focusing on the seriousness of initial conditions and prognosis. The donation proposal is communicated in a direct and simple way: "we propose to you an act of solidarity toward people who are in critical conditions. We propose to donate organs of your relative." Provide detailed information on the organ donation process and on its potential benefits. The proposal can be followed by a moment of privacy for the family to discuss and decide.

The Italian Transplant Coordination System monitors, audits and oversees organ donation, harvesting and transplant in our country. The Italian Transplant System controls organ donation, allocation and transplant; it is organized into three levels: National (National Transplant Center), Regional (Regional Transplant Center) and Hospital (Hospital Transplant Center). The Fondazione Agostino Gemelli Hospital Catholic University is one of the major regional

hospitals in Italy. As one of the five level-1 regional hospitals in Lazio, it has approximately 1600 beds and 95,000 accesses per year. It is one of the leading centers for identification of patients who have been declared dead with neurological criteria. Our intervention could have a beneficial effect on the rate of consent to organ donation (COD) by the relatives of brain-dead patients. To test this hypothesis, we compared the rate of COD before and after the implementation of the protocol into our ICU [13]. In our work we analyzed the family consent rate (potential and real donors' ratio) before and after the introduction of the new communication protocol. We observed that a consent rate increased from 71% in the pre-intervention period (2007–2012) to 78.4% in the post-intervention period (2013–2015) with a specific increase of 82.75% from 2014 to 2015. In 2017, we observed a consent rate of 78.6% with a steady rise in the number of identified potential donors. At the same time we registered the regional consent rate of 68.1 and 73.1% in 2016 and 2017, respectively. During these periods, no significant variation of organ donation consent has been recorded at a national level. Our center has kept a constant commitment in increasing the observation rates, keeping the opposition to COD rate unvaried at first and then contributing to reduce it significantly. On the whole, the center's opposition rate compared with both national and regional average is significantly lower: 2017: national, 28%; regional: Lazio, 27%; our ICU, 21% (**Figures 1 and 2**).



**Figure 1.** Brain deaths.



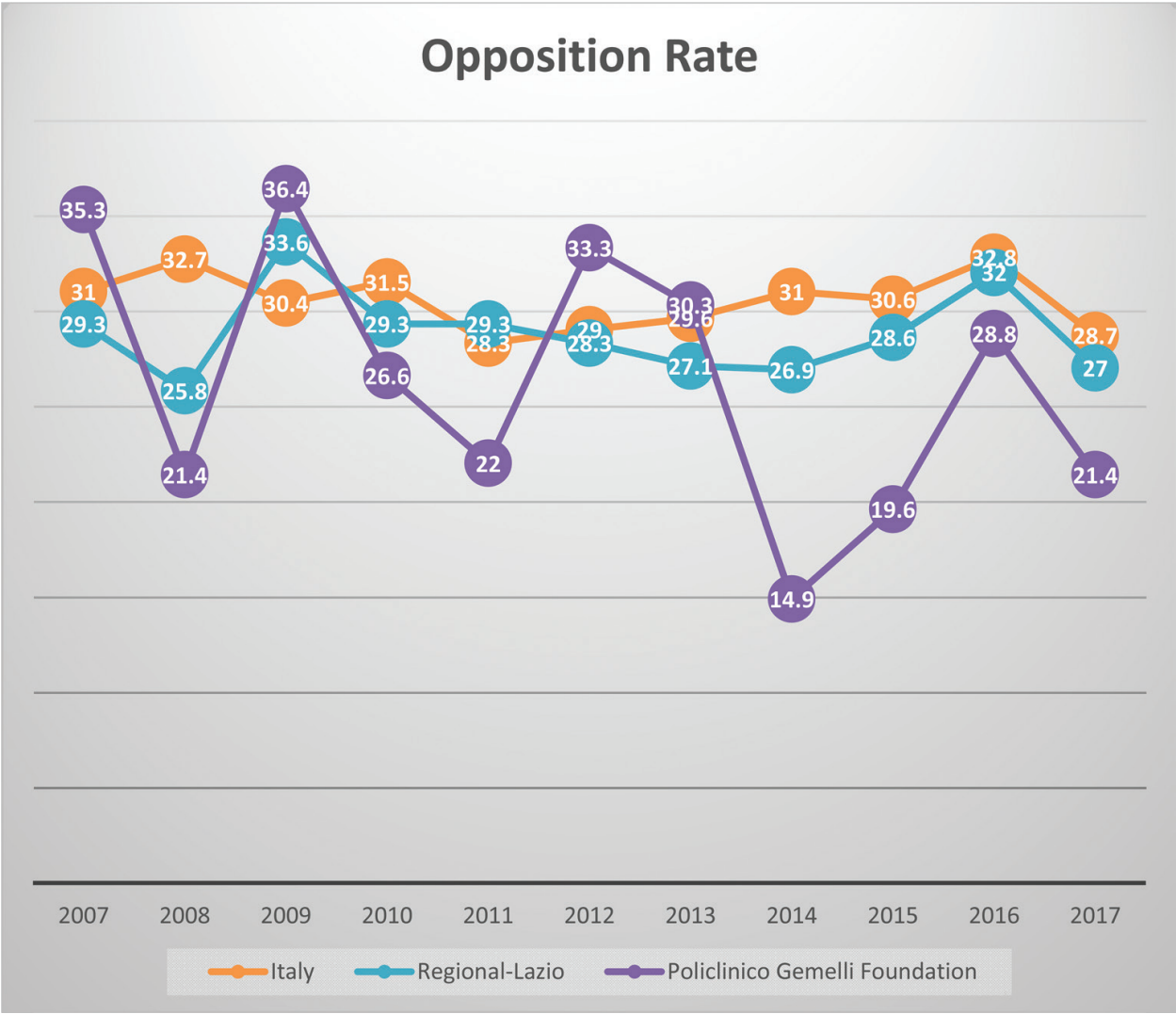


Figure 2. Opposition rates.

In our opinion, in order to suggest behavioral strategies to the care team involved in the assistance of potential donors and their family members, the following factors must be taken into account: family members are facing an acute event and high stress conditions; they may find different nursing teams and different people giving information they first learn about the life-threatening conditions and then about the death of the beloved. In this sudden critical situation, they are asked to take the place of the dear deceased, to make decisions about his body on his behalf. Family members have an extreme difficulty in contacting a condition of understandable reality. This is worsened by the fact of being in an unknown place, with unknown faces managing with emotions and personal convictions. Clinicians in the ICU should use structured approaches to communication including active listening, expression of empathy and considering the importance of explanation care. Communication is the process of sending or receiving messages through verbal and non-verbal means; therefore, an information field may consist of one or more subfields of information items such as thoughts, emotions and ideas. When, among individuals or among an individual and a group, there is a collaborative



and ongoing message exchange, aimed to understand each other, the communication is integrated in our social realities and we can define this process as “transactional.” In the transactional process the people involved in the act of communicating are actively and simultaneously sending information as well as receiving them. Participants perceive their communication as intentional. The information transfer between them takes place in a particular situation affected by relationship and culture. The speaker and the audience are co-communicators in the process with equal responsibility and power to create, as well as understand, a message. People encode their messages based on their own unique perceptions. Our past experiences, values, attitudes, knowledge, culture and feelings all influence our messages and also the way we interpret the messages of others. These influences are our unique perceptions or the way we see things around us. Before messages can be transmitted to another person or group, we must encode these messages. When the message is encoded it’s ready to be transmitted or sent to another person or group. The receiver must then interpret the message, by filtering the new information through his past experiences, culture, attitudes, values, knowledge and feelings. This interpretation is called decoding the message. The receiver decodes messages based on his perceptions, which are different from the sender. The sender needs to make sure that the receiver understood the message; therefore, it is the receiver’s job to convey a message back. The receiver’s reply to the sender is called feedback. The feedback allows the sender to ensure that the original message was interpreted correctly by the receiver. Feedback helps the communicators make sure that the message has been decoded correctly. Once the cycle has gone full circle, it will repeat itself for as long as the conversation continues. We could even say that sender and receiver change roles throughout the process depending on who is sending the message and who is responding to feedback. The location and the time (the situation) in which communication takes place are relevant and they influence the encoding and decoding process. The latter is paramount in an ICU, where deaths or losses of functional capacities of patients can take place unpredictably. Historically, trust in doctors has been an unconditional feeling. The clinician should know all the elements described that are particularly relevant in the relationship with the potential donors’ families. Family members often have difficulty understanding the condition of brain death. Their loved one still has a beating heart and a present breath (although assisted by the machine). The elaboration of death in this condition is not always simple. The doctor also needs to share the consent to the donation as soon as possible with the relatives. A narrative approach can be very useful to create a relationship of trust and support. The critical event causing the current situation is reported as telling a child a story already known. The narrative will describe the growing role of health-care workers who enter the history of the relatives and of the beloved. The care practitioners make supportive statements around non-abandonment and decision-making. We advise to remember the continuous need of feedback and of narrative approach. We also believe it is essential that ICU clinicians receive family-centered communication training as an element of critical care training to improve clinician self-efficacy and family satisfaction. These explanations promote a relationship in the here and now when both health-care practitioners and family members experience a state of stress and intense emotions. Knowing and seeing what is happening to the loved one, feeling part of and understanding the healing process is preferable to the anxiety generated by what is “unknown.” Family members are forced by their relative’s illness into an unwanted role, which provokes discomfort, dependence and anxiety. The relative is

vulnerable and asking for help; the doctor and the nurse, who are experts in medical care, take him or her in charge. Developing a good therapeutic and empathic relationship with the family, taking care of their emotional issues during this process, appears to lead families to opt for donation. The relationship with the care practitioners and family members can allow the creation of a sense of reality of the place and the moment. Then, it can make the relative aware of himself, of the event, of recognizing roles and responsibilities, to give permission to emotions and decision-making power to what is recognized as right and achievable. When considering patients in critical conditions admitted in the ICU, the care-taking process of the medical staff is addressed toward relatives more than toward patients, who continue to receive high-quality care. Clinically speaking, the communication-based relationship has a central role and a positive action on health improvement in the care process [18].

### 3. Conclusion

Further studies are needed to evaluate the effectiveness of an open intensive care unit and of a new systematic approach to communication between relatives and medical staff to decrease the rate of donation refusals. In our ICU, we applied this new approach based on the introduction of a multidisciplinary team and an increased attention for the patient and his family. In our single-center study, the higher increase in organ donations was registered in the 2014–2015 period, 1 year after the introduction of the new communication approach. This increase was also confirmed in the years following 2015. These results highlight the importance of effective communication with patient's relatives and the need to dedicate attention and time to them, especially in the ICU.

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