

Good Practice Guidelines

in the process of Organ Donation

GOBIERNO DE ESPAÑA
MINISTERIO DE SANIDAD, POLITICA SOCIAL E IGUALDAD
ONT

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National Transplant
Organization , 2011

That "Spain is the leader in organ donations" has become a national and international slogan. It is quite clear that our system has given ample proof of effectiveness and soundness and that our donation and transplantation activity has become a reference worldwide and is motive of pride for our professionals and our society. Furthermore, our system is also characterized by its continuous evaluation and improvement.

Our donation and transplantation activity, although growing in absolute terms, has remained stabilized in relative terms over the last decade. A significant number of patients are faced with long periods on the waiting list and, depending on the organ, 6 to 8% of these patients on the list die before receiving a transplant.

We are also experiencing times of fortunate epidemiological changes and changes in how society treats and confronts the end of life, changes that give rise to doubts on the stability over time of our potential for donation after brain death.

It was within this context that the initiative of the present project was born: Benchmarking applied to organ donation, specifically, to donation after brain death. 'Benchmarking' is a modern word used to refer to a practice that is as old as the human being: innately, we establish and try to learn from those who do it the best. The project has tried to identify those differentiating factors that justify some excellence results in the brain death donation process by our coordination team.

These factors are summarized in the present document with the single, and we believe commendable purpose, of helping our entire coordination network to improve their results in the process. These lines serve to acknowledge that this help is supported by the fantastic work carried out by the network and its continuing enthusiasm.

Rafael Matesanz

Director National Transplant Organization

Contents

I.	Introduction	9
II.	Recommendations on the composition of the hospital coordination team	*13*
III.	Recommendations on the ideal profile of the hospital transplant coordinator	*21*
IV.	Recommendations to improve the effectiveness of the referral of the possible donor to the critical care units	*25*
V.	Recommendations to improve effectiveness in the management of the possible donor in the critical care units	*39*
VI.	Recommendations to improve effectiveness in obtaining consent for donation	*47*
VII.	Annex 1: Benchmarking committee members	*63*



I

Introduction

Within the context of the *40 Donors PMP Plan* propelled by the *National Transplant Organization (NTO)* (in Spanish, Organización Nacional de Trasplantes) to improve the organ donation and transplant activity in our country, one of the strategies proposed is that of identifying, disseminating and implementing better practices applied to the process of donation after brain death.

The *Benchmarking*[1] methodology has been used in order to achieve this objective. Such methodology consists in defining a process and/or subprocesses, construct some indicators that represent the effectiveness in their development, identify the study units (in this case, hospitals authorized for organ procurement from the deceased) with the best indicators (references or benchmarks) and to investigate and describe the practices that may justify these excellence results, subsequently favoring their implementation, by adapting them to the needs and characteristics of other centers.

In order to put this initiative into practice, a committee formed by hospital and regional transplant coordinators and by members of the ONT was summoned. This committee designed the project and participated in the writing of the recommendations derived from it. The list of the Benchmarking Committee members is given in *Annex I*.

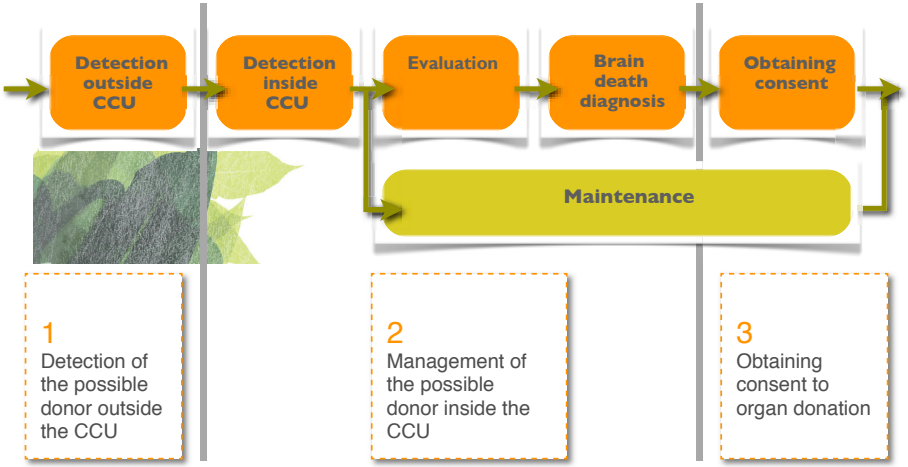


Figure 1: Structure of the process of donation after brain death: CCU: Critical Care Unit.

For this project, the process of donation after brain death within the hospital setting was structured into three subprocesses (Figure 1):

1. Camp RC. Benchmarking: The search for industry best practices that lead to superior performance. Milwaukee: Quality Press, American Society for Quality Control; 1989.

1. Referral of the possible donor to critical care units (CCU):

Detection of possible donors outside of the CCU has not been a usual area of work in our setting, at least not in a generalized way. However, early detection and subsequent referral to the CCU of possible donors may account for important differences in the ***potential for donation after brain death*** and therefore, in the final outcome of the process. The possible donor was defined as a ***person with severe brain damage and possible evolution to brain death in a short period of time***. The indicator used to evaluate effectiveness in this phase of the donation process was the percentage of deaths in the CCU out of all the deaths in the hospital with at least one of a series of ICD-9 codes among their primary or secondary diagnoses. This series of codes represents the etiology of 95% of brain deaths in our country[2].

2. Management of the possible donor in the CCU:

This is a subprocess which, in turn, includes a series of phases. Specifically, these are the detection of the possible donor within the CCU, clinical evaluation and maintenance of a brain dead person, as well as brain death diagnosis. As an indicator of the effectiveness of this subprocess, the percentage of appropriate donors for the extraction (pending consent) was calculated out of the total number of persons with clinical examination consistent with brain death within the CCU. The data were obtained from the *Quality Assurance Program in the Donation Process*[3].

3. Obtaining consent to proceed to donation:

Effectiveness in this phase was evaluated using the percentage of consents to donation obtained from the total number of eligible organ donors, pending consent. Once again, the data needed for the construction of the indicator were obtained from the *Quality Assurance Program in the Donation Process*[3].

2. Cuende, N, Sánchez, J, Cañón, JF, et al. Mortalidad hospitalaria en unidades de críticos y muertes encefálicas según los códigos de la Clasificación Internacional de Enfermedades. Med Intensiva, 2004; 23(1): 1-10.

3. Programa de Garantía de Calidad en el Proceso de la Donación. Web page of the Organización Nacional de Trasplantes. Available at: http://www.ont.es/infesp/Paginas/ProgramadeGarantiadeCalidad.aspx. Last access: November 2010.

The study setting included all those hospitals authorized for organ procurement in Spain. In order to participate in the project, the hospitals had to fulfill the requirement of having participated in the *Quality Assurance Program in the Donation Process* for at least 3 years out of the 5 years (2003 to 2007) included in the study period. A total of 104 hospitals participated in the study, this number accounting for 68% of the hospitals authorized for donation in our country, although these hospitals accounted for approximately 80% of the donors of the period studied.

After having constructed the indicators for each one of the participating hospitals, each one of the subprocesses and of each one of the years of study, those centers with excellence results in each one of the phases were identified. Those hospital factors having an influence on the indicators were taken into account. The hospitals were grouped by these hospital factors in order to be comparable. Next, a questionnaire designed for the description of their practices was sent to the hospital coordination teams of these centers. Two members of the *Benchmarking* Committee visited each one of these hospitals and filled out the corresponding questionnaire with the coordination team of the center. After, the *Benchmarking* Committee analyzed and discussed these questionnaires in order to extract information on the practices that could justify these excellence results.

As a consequence of this exercise, the Committee has elaborated a series of recommendations to achieve greater effectiveness in the process of donation after brain death that are expressed in this document. A justification has been provided for each one of the recommendations, mentioning the description of the findings in the hospital selected by their results, when pertinent. It is important to stress that it was not aimed to offer detailed step-by-step information of each one of the subprocesses analyzed but rather of those ***actions differentiating them*** from those performed in the rest of the hospitals, probably critical factors ***for obtaining excellent results***.

The recommendations derived from this project are aimed at the entire coordination network, hospital administrations and heads of hospital units, directly or indirectly involved in the donation process.[4] The purpose is to communicate these practices so that the recipients of these recommendations can evaluate the possibility of incorporating them as far as possible and with the necessary adaptations to their work methodology.

4. Those readers of this guide who are interested in having more detailed information on the methodology used, on the actions performed in the hospitals identified in this study, on the protocols or guidelines used in them, or any additional information, please do not hesitate to consult at: ont@mspsi.es

Recommendations



II

On the composition of the hospital coordination team

RECOMMENDATION 1:

THE NUMBER OF MEMBERS AND THE COMPOSITION OF THE COORDINATION TEAMS SHOULD BE ADAPTED TO THE COORDINATION NEEDS OF EACH HOSPITAL

Addressed to: Hospital Administration; CCU Responsible Persons; Hospital Transplant Coordination; Regional Transplant Coordination

The number of members and composition of the coordination team vary in the hospitals selected based on the coordination needs of each hospital. The number and characteristics of the teams have varied over time, this responding to the characteristics of each hospital.

It is very important for the existing regional coordinator and coordination team to have in-depth knowledge about the possibilities and needs of the center. Furthermore, a very good relationship needs to be established with the hospital administration so that it understands the importance of donation and transplantation and therefore understands and allots the necessary human and material requirements to cover these activities.

In most of the centers selected, the team is formed by ***medical and nursing personnel***, with a greater percentage of physicians in the first two subprocesses (referral to CCU and management within the CCU). Most of the medical staff are intensivists. However, it should be stressed that the emergency physicians are also present in the first subprocess. In the second subprocess, only intensivists are present. In the third subprocess, it is found that some nephrologists and anesthetists are also present. The origin of the ***nursing staff*** is more ***varied***, these more frequently being from ***surgery in the second indicator and from nephrology in the third.***

RECOMMENDATION 2:

ALL OF THE TEAM MEMBERS SHOULD RECEIVE TRAINING IN COORDINATION AND COMMUNICATION COURSES

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

Almost all of the coordination team members of the centers selected have taken training courses as transplant coordinators and communication courses. In many cases, the team members are even teachers of these courses.

RECOMMENDATION 3:

IT IS RECOMMENDED THAT THERE SHOULD BE A STABLE COORDINATION TEAM OVER TIME

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

In most of the coordination teams, there is at least one *professional with more than 10 years of coordination experience*, the mean years of seniority of the team being superior in the third subprocess, especially in regards to the nursing staff. Therefore, the existence of certain stability in the coordination team is important. Experience plays an essential role in all of the project phases and very especially in obtaining consent for the donation.

RECOMMENDATION 4:

THERE SHOULD BE AT LEAST ONE MEMBER OF THE COORDINATION TEAM HAVING HIERARCHICAL RESPONSIBILITY IN THE HOSPITAL

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

In several of the hospitals in which excellence results were found, section/service chiefs are part of the medical staff making up the transplant coordination team. This occurs in a lower proportion in subprocess 1, and in half of the hospitals in the subprocesses 2 and 3. There are also supervisors among the nursing staff, especially in phases 2 and 3 of the donation process.

The recommendation provided does not imply that having a position of responsibility in the hospital is a requirement to opt for transplant coordination. However, based on the observation of the centers, it is deduced that matching the coordination and hierarchy facilitates decision making and therefore, the improvement of the effectiveness in the donation process.

RECOMMENDATION 5:

IT IS ADVISABLE FOR THE COORDINATORS TO HAVE PARTIAL DEDICATION TO THE COORDINATION TASKS

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

Most of the transplant coordination staff of the centers identified have partial dedication to the coordination tasks, all of them in the case of subprocess two. In the hospitals that have a person with full-time dedication, this is generally because of the extra workload related with the transplantations teams. Therefore, *full-time dedication of some of the team members is recommended in those centers having a large work load associated to the transplant activity.*

In every case, the part time dedication of the professionals is combined with activities related to their professional category.

RECOMMENDATION 6:

IT IS NECESSARY TO PERMANENTLY COUNT ON THE PRESENCE, EITHER BY BEING ON DUTY OR ON CALL, OF THE COORDINATORS WHO CAN ASSUME RESPONSIBILITY IF A DONOR APPEARS

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

The number of times the team members are on call depends on the number of team members. In general, this is based more on availability than on physical presence. The coordinator assumes the responsibility when any donor appears. On occasions, the coordination duties are shared with care work, (e.g. usual critical care on duty tasks), although this care work is relegated to a secondary level if a possible donor appears.

In the second subprocess, at least one physician is always on call.

RECOMMENDATION 7:

THE COORDINATORS MUST HAVE FULL DECISION CAPACITY

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

To achieve good results in the donation process, it is essential to have full decision capacity regarding the possible donor in all of the phases of the process. It is desirable for the Coordination Team to be able to participate in the decision to admit the patient to the CCU and the autonomy to request the necessary tests, to negotiate the availability of the operating room, etc. Depending on the structure of the coordination teams, the work distribution is different. In the teams formed by a physician and nurse, the physician performs the clinical work and the nurse the logistic work.

RECOMMENDATION 8:

IT IS ADVISABLE FOR THE COORDINATORS TO CONSIDER THAT THEY ARE CORRECTLY COMPENSATED AND RECOGNIZED PROFESSIONALLY

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

In practically all of the centers analyzed, the coordination teams felt that they were somehow compensated for the large workload entailed by the coordination. It is important for the administrations to recognize that the transplant coordination work within the hospital is essential. That is why it is important to not only recognize this work economically but also as a merit within the professional career.

RECOMMENDATION 9:

THE COORDINATION TEAM MUST BUILD AND MAINTAIN A GOOD RELATIONSHIP WITH ALL THE HOSPITAL PERSONNEL

Addressed to: Hospital Transplant Coordination; Hospital Administration; Responsible for Other Units

It is advisable for the coordination team to attend to all of the queries received from the hospital staff with a positive attitude, helping to resolve any problem. They become ***solvers and facilitators*** in all of the subjects related with donation and transplantation. The coordination team should be known by and be a ***reference for all the hospital***, constituting the contact point for any problem or doubt related with the coordination.

A good relationship must be maintained with the rest of the hospital. The hospital personnel should be made aware of the donation and transplant, facilitating the uninterrupted course of all the process. Participation of several hospital services in the donation process is increasingly more frequent. It is considered to be advisable to go towards collaboration-type models with these units, this favoring the sensitivity of the hospital as a whole.

Although it is considered important to establish relationships with the entire hospital, some of the selected coordination teams stress the importance of sharing their statistics, especially with the Hospital Administrations and with those services that most frequently collaborate with the transplant coordination (Laboratories, Pathology, Radiology, Emergency Service, Internal Medicine, Neurology, etc.).

Recommendations



III

On the ideal profile of the hospital transplant coordinator

As a common element to the three phases of the process in the hospitals selected, it has been seen that the coordinator forms a central axis around which all the donation process structure is constructed. Although some specific characteristics of the aspects analyzed appear in each one of the subprocesses, a series ***of common traits and skills*** that frequently appear in the individuals making up the coordination team of the selected hospitals are found. These are considered to be important in order to achieve excellent results in the coordination tasks.

It is very difficult to speak about recommendations in this case, although these characteristics should be taken into account when selecting a new transplant coordinator or when training them to improve these qualities. The fundamental importance of the ***work of the regional transplant coordinator and the hospital administration*** in the selection of the hospital coordinators and their capacity to motivate them should be stressed.

RECOMMENDATION 10:

IDEAL PROFILE OF THE HOSPITAL TRANSPLANT COORDINATOR

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

Motivation, dedication and work capacity, words that are often heard when speaking about the activity of the coordinators interviewed, stand out. The enthusiasm and capacity to transmit this in order to successfully perform the work characteristic of the coordination and to achieve a ***good response in the face of the pressure***, so often present in the donation process, is very positive.

Another highly valued quality is the *capacity for response*. The team should be made of persons with problem-solving capacity, this implying *knowledge*, both of the hospital setting as well as the characteristics of the donation process, for which extensive training and pedagogic attitudes are required.

Versatility is greatly related to the above, as each process is different. The search for solutions for the diversity of situations requires great *creativity and capacity for improvisation*. The coordinator should be capable of coping with any new situation that may arise.

It is very important for the members of the coordination team to have *leadership* qualities, with *presence and availability* for the hospital staff. They should have *communication skills, good capacity for relationships and empathy,* all of these being of great help.

Recommendations



IV

To improve the effectiveness of the referral of the possible donors to the critical care units

RECOMENDACIÓN 11:

THE EXISTENCE OF A PROGRAM SPECIFICALLY ORIENTED TOWARDS THE TREATMENT OF THE NEUROCRITICAL PATIENT IMPROVES THE EFFECTIVENESS OF THE REFERRAL OF POSSIBLE DONORS TO THE CRITICAL CARE UNITS (CCU)

Addressed to: Hospital Administration; Responsible Person of Units outside of the CCU that attend to patients with severe brain damage; CCU Responsible Persons, Hospital Transplant Coordination; Regional Transplant Coordination

The hospitals with the best results in this phase of the process stand out for having developed a program oriented towards the optimization of the treatment of the neurocritical patient, and not a specific program for the referral of possible donors to the CCU.

In the optimization of the treatment of the neurocritical patient, identification of the patient with severe brain damage and its early communication to the CCU for the subsequent evaluation of the case and possible admission to said units is contemplated as a fundamental step.

In the following, the recommendations oriented towards the development, implementation and maintenance of said program are specified.

Recommendation 11.1:

In the development, implementation and maintenance of said program, all of units outside the CCU attending to patients with severe brain damage must be involved

Addressed to: Hospital Administration; Responsible Persons of Units outside the CCU attending to patients with severe brain damage; CCU Responsible Persons

For a program oriented towards the optimization of the treatment of the neurocritical patient to function adequately, it is important for ***all of the units outside of the CCU that usually attend to the patient with severe brain damage*** to be involved in its development, implementation and maintenance.

The unit that must be counted on fundamentally is the ***Emergency Service***. However, there are other units that can be potentially involved in this program, depending on the type of hospital, such as the following:

- *Neurosurgery Service*
- *Neurology Service (including the emerging Stroke Units).*
- *Internal Medicine Service*

The possibility of including ***other hospitals, both private and public, for which a specific hospital acts as reference***, in this program, for the care of neurocritical patients, should also be evaluated.

On the other hand, participation of the ***Community Emergency Services*** should be promoted.

Recommendation 11.2:

In the CCUs, it is essential to generate the habit of decisions based on discussion and consensus in regards to the management for each patient, in general, and in regards to the neurocritical patient and possible donor, specifically

Addressed to: Responsible Persons and Personnel of the CCUs.

Generating the habit of making decisions after having a discussion and reaching a consensus can be achieved by holding ***periodic clinical sessions*** that include all of the CCU personnel. It is important to favor fluent ***communication*** within the units, both inside and outside of these sessions. Doing so helps to generate common practices and attitudes, including those regarding organ donation.

Recommendation 11.3:

The donation should be included in the CCU service portfolio

Addressed to: Hospital Administration; Regional Transplant Coordination; CCU Responsible Persons

In order to favor common attitudes in the hospital and within the CCUs regarding organ donation, it is very important for the hospital to consider it as a ***comprehensive medical process within the portfolio of the CCU services.***

Recommendation 11.4:

It is recommendable to implement an action protocol oriented towards the identification of patients with severe brain damage and its early communication to the CCUs

Addressed to: Hospital Administration; Responsible Persons of Units outside of the CCU attending patients with serious brain damage; CCU Responsible Persons. Hospital Transplant Coordination; Regional Transplant Coordination; Care Ethics Committee.

It is important for the hospital to have an action protocol oriented towards the identification of patients with severe brain damage and its immediate communication to the CCUs. Such a protocol does not necessarily imply the admission of the patient in the CCU. However, it does imply the evaluation of the case and therefore of the individual benefit of each admission either with a therapeutic objective or for the purpose of donation, according to the patient's baseline condition and prognosis. Regarding this action protocol:

- It should be put into practice as a ***care concept***, with the specific purpose of ***optimizing the management of the neurocritical patient***, and in which this type of patients are considered to be of ***priority***.

- All of the units attending to this type of patients should participate in its elaboration. It must be a protocol that has been developed by ***consensus***.

- The ***clinical triggers*** that should activate the communication of the existence of these patients to the CCU by the units outside the CCU must be clearly defined. Specifically, the protocol should specify what the starting point is on the Glasgow Scale (e.g. ≤8) to activate this communication. Furthermore, this communication should always occur, ***independently of the patient's age, associated comorbidity and prognosis***.

- Once the clinical trigger has been specified, the protocol should detail the action that the physician and/or nurse who identifies the corresponding case must carry out and special emphasis should be placed on the ***notification system (immediate call)***, using the mechanism foreseen in the hospital, to the CCU.

- The action protocol must also contemplate the ***immediate call to the transplant coordination team when possible donors are identified.*** This call can be applicable to all patients with ***severe brain damage*** and not be exclusively limited to possible donors. The call to the Transplant Coordination Team can be made either directly from the unit outside of the CCU that has identified the case or from the CCU once alerted. It is recommendable for the Transplant Coordination to form a part of the decision-making process for the admission of possible donors in the CCU. This is especially important in those cases in which there are doubts about the presence of absolute or relative contraindications for the donation. In this way, the Transplant Coordinators can make an early and individualized evaluation of the cases, which facilitates the decision for the rest of the units involved. In any case, the intervention of the Transplant Coordination must always be understood as by consensus with all the professionals involved.

- It should be implemented ***independently of whether the possible donor*** is inside or outside of the hospital (hospitalization units, emergencies, peripheral hospitals, etc.).

- It should be ***available in writing.***

- The protocol should include the ***possibility of organ donation*** as a medical reason for admission of a patient in the CCU.

- The ***information to the family*** on the prognosis and admission of a patient in a CCU as a possible donor should be ***truthful*** and be provided ***clearly, although progressively, and should be adapted to the rhythm of assimilation of the situation***. Therefore, it is recommended to make an individualized evaluation of the time and circumstances in which this information is provided. .

- The *training activity* oriented at its practical implementation, an activity that must be aimed at units that attend to patients with severe brain damage (and peripheral hospitals and community emergency services, if appropriate), should be promoted. The distribution of *training material* on this action protocol is very adequate. Training material must include decision algorithms that stand out for their *simplicity and rapid understanding*.

Recommendation 11.5:

It is recommendable to have protocols on the limitation of life sustaining therapy (LLST)

Addressed to: CCU ad hoc Committee; Care Ethics Committee

These protocols must also be by *consensus* with all the CCU staff. A *multidisciplinary* committee should be available for its preparation, including the nursing staff and experts in bioethics.

The protocol should specify the importance of decision making reached by consensus for the application of the LLST, in which all the personnel attending to the corresponding patient are involved.

The existence of these protocols greatly helps the staff participating in the admission of possible donors in the CCU in clinical decision making, systematization of the information to be provided to the relatives of the possible donors and the action to take if there is no evolution to brain death.

Recommendation 11.6:

Performing audits outside the CCU to evaluate and monitor the effectiveness of referral to the CCU of possible donors and identify areas of improvement is a recommendable activity

Addressed to: Hospital Administration; Responsible CCU; Responsible Person of Units outside the CCU that attend to patients with serious brain damage; Hospital Transplant Coordination; Regional Transplant Coordination

The performing of periodic audits to units outside the CCU that attend to neurocritical patients is necessary to evaluate and monitor the effectiveness of this phase of the process and to identify areas of possible improvement. These audits, consisting in retrospective clinical chart reviews, should also be done by consensus with the units involved and with the sole purpose of continuing improvement.

This work can be extended to peripheral, public and private hospitals (and their CCU) for which a certain center is of reference.

Recommendation 11.7:

It is recommendable to manage the CCU resources in such a way as to facilitate care to the possible donor

Addressed to: Hospital Administration, Responsible CCU; Responsible Persons of Units outside the CCU attending to patients with serious brain damage; CCU Responsible Person. Hospital Transplant Coordination

Bed availability for admission of the possible donor to the CCU is considered one of the main limitations to obtain good effectiveness in this donation process phase. The generalization of the concept of neurocritical patient (including possible donors) as a priority patient is of special relevance. This must be complemented with good management of the CCU beds, which is generally sufficient to solve this potential problem, including the provision of beds belonging to the intermediate units. In this sense, the support of the Center Administration is fundamental. Under the possibility of lack of beds in a CCU and a possible donor identified outside of the unit:

- The development of the donation process outside of the CCU must be facilitated through adequate cooperation between the unit outside of the CCU and the CCU-Transplant Coordination team.

- When it is impossible to carrying out any of the previous measures, it is recommended to negotiate the transfer of the possible donor to a nearby hospital with immediate capacity of admission in the CCU.

RECOMMENDATION 12:

THE DEVELOPMENT OF TRAINING, PROMOTIONAL, AND EDUCATIONAL ACTIVITIES ON DONATION AND TRANSPLANTATION AIMED AT THE PROFESSIONALS OF THE CCU AND OF THE UNITS OUTSIDE OF THE CCU THAT ATTEND TO NEUROCRITICAL PATIENTS IS RECOMMENDABLE

Addressed to: Hospital Administration; CCU Responsible Person; Responsible Persons of the Units outside of the CCU attending to patients with serious brain damage; Hospital Transplant Coordination

The *concept of donation* must be promoted as:

- *A medical process that forms a part of the usual end-of-life care*
- *A medical cause of admission in a CCU*
- *A shared process,* not exclusive to the Transplant Coordination.

In the following, specific recommendations are provided aimed at promoting this concept in the hospital setting, in general, and in the outside of the CCU setting, specifically.

Recommendation 12.1:

The development of training sessions on the donation and transplant process targeted to the units outside of the CCU that attend to neurocritical patients is a highly recommendable activity.

Addressed to: Responsible Persons of the Units outside of the CCU attending to patients with serious brain damage; Transplant Hospital Coordination; Hospital Administration

The performing of ***training sessions*** on the donation and transplant process targeted to the units outside of CCU that attend to neurocritical patients (including peripheral hospitals and community emergency services, if appropriate) is a highly recommendable activity. These training sessions must systematically include all the staff, both medical and nonmedical, of these units.

Within the training sessions, the teaching support that may be provided to these units in aspects regarding ***the dying process and accompany the family in their mourning*** by The Transplant Coordination staff can be important. This is an area in which the Transplant Coordinators have privileged training and experience and which, at the same time, is fundamental in the day-to-day work of the professionals in the units outside of the CCU that attend to critical patients.

This training effort can be complemented with the distribution of ***written material*** on donation and transplantation to the units outside of the CCU. In this sense, the material produced periodically by the hospital, regional and national coordinations should be proactively distributed among the personnel of the Units outside of the CCU that attend to patients with serious brain damage.

Recommendation 12.2:

The performance of periodic visits by the Transplant Coordination to the units outside of the CCU that attend to patients with severe brain damage is fundamental.

Addressed to: Hospital Transplant Coordination

The performance of ***periodic visits*** to the units outside of the CCU that attend to neurocritical patients by Transplant Coordination is fundamental. In this way, fluent personal relationships are promoted and a reminder function is made on the important role played by the personnel of these units in the phase of early detection and referral of the possible donors to the CCU.

Recommendation 12.3:

Performing continuing feedback work on the donation and transplant activity to the units outside of the CCU is important

Addressed to: Hospital Transplant Coordination; Regional Transplant Coordinations

The periodic feedback to the units outside of the CCU on the donation and transplant activity is considered to be very important, either carried out within the previously-mentioned training sessions or more informally. This feedback should consist in providing information on:

- The donation activity and the results of transplantation, in general.

- The specific cases of possible donors referred to the CCU in the corresponding hospital: if they have become actual donors or not, the reasons and the patients who have benefited from the donation act.

This activity is considered important in order for the personnel from the units outside of the CCU who attend to neurocritical patients to feel that they are fully involved in the process and to generate a "feeling of pride" in said personnel by their active participation.

The ways of reinforcing this feedback activity are varied. For example, mention can be made of the sending of letters in a short time period by the Transplant Coordination to the unit that has participated in the detection of a possible donor and in its referral to the CCU, informing them of the result of the donation, when it occurs.

Recommendations



V

To improve effectiveness in the management of the possible donor in the critical care units

RECOMMENDATION 13:

ALL THE MEDICAL PROFESSIONALS FROM THE CRITICAL CARE UNITS MUST ACTIVELY PARTICIPATE IN THE DETECTION OF POSSIBLE DONORS WITHIN THE CCUs

Addressed to: CCU Medical Professionals, CCU Responsible Persons, Hospital Transplant Coordination

In regards to the detection of possible donors, it is recommended that all of the CCU medical professionals should be actively involved in the identification of patients with severe brain damage, in general, and in the identification of potential donors, specifically. In order to facilitate this involvement:

- Spreading the idea that the ***donation is a part of the CCU functions*** and of the ***end-of-life cares*** is essential. To do so, it is important for the hospital to recognize that the donation forms a part of the CCU service portfolio.

- It would also be useful to hold ***clinical sessions in the CCU in which the cases admitted to hospital are discussed***, including those with possible evolution to brain death. In these sessions, it is important to facilitate decision-making reached by consensus on the clinical approach, the possibility of donation or the need for LLST, according to the circumstances of the case.

RECOMMENDATION 14:

TO FACILITATE DETECTION OF POSSIBLE DONORS, IT IS RECOMMENDABLE FOR THE HOSPITAL TRANSPLANT COORDINATOR TO BE INVOLVED IN THE FOLLOW-UP OF ALL THE NEUROCRITICAL PATIENT

Addressed to: CCU Medical Professionals, CCU Responsible Persons, Hospital Transplant Coordination

Several of the hospitals with better results in this phase of the process consider it to be advisable for ***the transplant coordinator (when he/she is an intensivist) to always keep track of the follow-up of every neurocritical patient*** in order to facilitate the detection of possible donors in the CCU.

RECOMMENDATION 15:

IT IS ESSENTIAL FOR ALL THE MEDICAL PROFESSIONALS OF THE CCUs TO ASSUME RESPONSIBILITY FOR THE DIAGNOSIS OF BRAIN DEATH, THE CLINICAL EVALUATION AND MAINTENANCE OF THE POSSIBLE DONOR, THIS ALWAYS BEING DONE IN COLLABORATION WITH THE TRANSPLANT COORDINATOR

Addressed to: CCU Medical Professionals; CCU Responsible Persons; Hospital Transplant Coordination

It is essential for the medical professionals of the CCUs to assume responsibility of a potential donor in all of the phases of the process, counting on, of course, adequate nursing staff and on the Transplant Coordinator.

The decision to rule out a donor should always be reached by consensus with the Transplant Coordinator. Although it is important for all the medical professionals of the CCUs to participate in the evaluation of the possible donors and to be familiarized with absolute contraindications regarding organ donation, said evaluation should always be performed in close collaboration with the Transplant Coordinator. In this way, losses in the process due to inadequate medical contraindications are avoided or minimized.

RECOMMENDATION 16:

IT IS IMPORTANT TO DEFINE THE PERMANENT AVAILABILITY OF MEDICAL SPECIALISTS IN NEUROLOGY, NEUROSURGERY AND/OR NEUROPHYSIOLOGY FOR THE DIAGNOSIS OF BRAIN DEATH

Addressed to: Hospital Administration; Hospital Transplant Coordination; Regional Transplant Coordination

It is recommended that if the center cannot rely on the permanent presence of these professionals (24h/365d), the shifts of the specialists should be specified. It should also be specified how to contact them in order to be able to request their collaboration, when necessary, This information should be easily assessable for all of the CCU staff.

RECOMMENDATION 17:

IT IS RECOMMENDED THAT THE HEALTH CARE CENTER HAVE A TRANSCRANIAL DOPPLER

Addressed to: Hospital Administration; CCU Responsible Person

When providing the diagnosis of brain death, it is essential to be able to count on the possibility of a blood flow test. In this sense, it is recommended that the centers authorized for the donation process should have a transcranial doppler as well as professionals trained in the management and interpretation of this diagnostic technique.

RECOMMENDATION 18:

A MICROBIOLOGY LABORATORY AND PATHOLOGY LABORATORY SHOULD ALWAYS BE AVAILABLE

Addressed to: Hospital Administration; Regional Transplant Coordination; Hospital Transplant Coordination

If the center does not have a permanent microbiology laboratory or a pathology laboratory (24h/365d), then it is recommended that this center should have a plan established for the sending of samples to a reference laboratory. In this way, the need to improvise when faced with complicated or special situations when making an adequate clinical evaluation of a possible donor is avoided. This information should be easily assessable to all of the CCU personnel.

RECOMMENDATION 19:

IT IS IMPORTANT TO HAVE WRITTEN PROTOCOLS REGARDING THE DETECTION, EVALUATION AND MAINTENANCE OF POSSIBLE DONOR AND THE DIAGNOSIS OF BRAIN DEATH

Addressed to: CCU Responsible Persons; CCU Personnel, Hospital Transplant Coordination

Those hospitals standing out for their effectiveness in the intra-CCU management of possible donors have written protocols regarding the different phases of the donation process that take place within the CCUs.

Not only should these protocols be available but the medical personal and nonmedical personnel of the CCUs should be familiar with their content. These protocols should be also easily accessible to all of the professionals involved. These protocols should be periodically updated.

Training should be carried out for all of the CCU personnel that would make it possible to put these protocols into practice.

RECOMMENDATION 20:

IT IS IMPORTANT TO HAVE A GOOD WORK ENVIRONMENT AND FLUENT COMMUNICATION WITHIN THE CCUs

Addressed to: CCU Responsible Persons; CCU Personnel; Hospital Transplant Coordination

It has been seen that the best results are registered in units with a good work ambient between all of the professionals involved. This facilitates the active involvement of all the professionals in the donation process.

Several aspects have been identified by the professionals of the center selected as key points:

- Good work environment between the medical professionals.
- Good medical-nurse communication/relationship.
- Team work.

RECOMMENDATION 21:

CONTINUING EDUCATION OF ALL THE PERSONNEL IN THE CRITICAL CARE UNITS IN THE ORGAN DONATION PROCESS IS AN ESSENTIAL ELEMENT

Addressed to: CCU Responsible Persons; CCU Personnel; Regional Transplant Coordination; Hospital Transplant Coordination

It is recommended that specific and continuing education in donation and transplant of all the health care professionals working in the CCU be promoted.

The training of the resident physicians in the setting should be encouraged.

This training effort should be carried out by all of the levels of the health care administration, that is on the national, regional and hospital levels.

Recommendations



VI

To improve effectiveness in obtaining consent for donation

RECOMMENDATION 22:

THE INTERVIEW WITH THE FAMILY MEMBERS OF THE POSSIBLE DONOR SHOULD FOLLOW A SPECIFIC METHODOLOGY AND SHOULD BE PLANNED AS MUCH AS POSSIBLE

Addressed to: CCU Responsible Persons; CCU Personnel, Hospital Transplant Coordination

Although each interview is different, a methodology with sequential, clearly defined phases that should not be mixed should be used.

Recommendation 22.1:

The interview should always be prepared. It is important to obtain information on the family, plan the site where the interview will be conducted and how the death will be communicated, notify the family in good time and organize the necessary human and material resources

Addressed to: CCU Personnel; Hospital Transplant Coordination

The centers consulted recommend ***preparing any aspect related with the interview that may influence its result***, reducing the need to improvise as much as possible.

Those elements that these centers recommend to prepare ahead of time are mentioned in the following:

- It is important to speak with the professionals who have attended to the possible donor to *gather information on the family* (without interpreting or prejudging the result). It is possible to know in advance if it will be necessary to count on *cultural cooperators* and/or *translators*, or who are those *persons necessary* to make the decision on donation.

- The *direct family members should be informed that it is important for all of them to come to the center* to receive information regarding the situation and prognosis of the patient. This request makes it possible for everyone who should be included in the decision to come. If necessary, it should be stressed that it is important that all of the family members come with sentences such as "It would be best if they come; it is better for me to explain it to them".

- When there are social, cultural or idiomatic type barriers or difficulties, the *support of cooperating persons, translators and friends* of the possible donor with a greater level of integration or of *religious references* whose cooperation may be beneficial for the family can be foreseen. These persons should be previously informed about the donation so that they can support the family and maintain a favorable attitude and not be limited to making a simple translation.

- It is important to provide the family with a private room, where they can speak *freely*, and *not far from the donor*, since they frequently request to see him/her.

- The *interview should be prepared with the professional who is going to communicate the death.* This is usually the medical professional who has been responsible for the patient. However, if this is not possible, a medical professional from the same service should be sought, ideally someone trained in communication techniques. *The information that will be given to the family and how to communicate it, including the communication of the death, should be prepared.*

- If the condition of the donor or the situation of the family allows for it, it is preferable to *avoid conducting the interview at night*. They are generally more rested and more receptive during daylight. (See recommendation 24.2)

Recommendation 22.2:

It is not appropriate to limit the number of persons who participate in the interview. All those persons who are important for the decision should be present and contact should be maintained with them

Addressed to: CCU Personnel; Transplant Hospital Coordination

All those persons who are important when making the decision should be present. The exclusion of anyone could entail the risk of excluding those who are relevant.

It is recommendable to *identify all those who*, due to their close relationship to the donor or their leadership position or capacity, *may have greater influence in the decision of the group*.

The coordinators *should not lose contact with anyone in the group*. During the interview, the group should not be allowed to split up. Therefore, if someone wants to leave for a short time, this person should not be prevented from doing so (one of the coordinators can accompany this person), but they should return, since a unanimous decision is required, without discrepancies within the group.

Recommendation 22.3:

It is recommended that prejudging the result of the interview should be avoided and an attempt should always be made (except in those cases in which it is known with certainty that the transplant will not be performed). Furthermore, no maximum time for the interview should be pre-established

Addressed to: CCU Personnel; Hospital Transplant Coordination

- The hospitals consulted answered unanimously that the ***interview should always be conducted, except when it is known that the transplant will not be done***, for example, when there are no appropriate recipients in the case of an infant donor.

- The variability in the interview duration is considered to be enormous. Limits regarding the duration of the interview should not be established beforehand.

Recommendation 22.4:

It is very important to establish a professional helping relationship that facilitates the necessary trust so that the relatives accept the option for donation. To do so, it is essential to know and to use the communication tools

Addressed to: CCU Personnel; Hospital Transplant Coordination

Establishing a good relationship with the family based on transparency, empathy, emotional support and the professional helping relationship is considered to be very important. ***The helping relationship should be created with the relatives from the beginning and maintained during the entire interview.*** It is also recommendable to use ***communication elements***, such as open questions, reflection of emotions, active listening or paraphrasis.

During the interview, it is advisable to let them talk without interfering and to respect their silences. Physical contact is important if the family shows that they require it.

At the end of the interview, it is important to continue maintaining the helping relationship with the family until the interview is over. This should end with signs of condolence and affection, independently of its outcome.

Recommendation 22.5:

The interview is structured into a series of successive and independent phases: initiation, communication of death, request for consent to donation, and completion. These phases of the interview should not be mixed and it is important to make sure that the family has understood the fact of death before requesting the consent

Addressed to: CCU Personnel; Hospital Transplant Coordination

Several teams consulted recommend that the *team that intervenes in the interview* should be made up of the *medical professional* who has been responsible for the patient (or another from the same service, if this is not possible) who will be *in charge of communicating the death* and by *two persons from the transplant coordination team*, usually one physician and one nurse, with training in communication techniques. Alternatively, if there are only two persons, one will communicate the death and the other will request the consent for donation.

It is considered to be very important t*o establish the helping relationship with the family from the beginning and to maintain it to the end* since according to the experience of the centers interviewed, in addition to the support that this relationship supposes for the family in very difficult moments, it increases the likelihood that the family will accept the donation.

The medical professional who is responsible for the patient should be the one who begins the interview and presents the coordinator team by their first and last names. However, they still should not be introduced as transplated coordinators, except under exceptional situations (for example, the previous request for donation by the family).

Once the interview has been initiated, the intensivist, with the support of the coordinators, can proceed to the communication of death (See Recommendation 22.6.)

Once the death has been communicated, the person responsible for directing the interview can gradually take on a more background position, so that the coordinators *can assume a more important role in the communication with the family.* The person who has communicated the death can leave the room and attend to other work, explaining it to the family.

Before going on to the request for donation, it is very important for the coordinators *to assure that the family has understood the fact of the death.* If this is not so, they should continue to give the necessary explanations that will help them to accept the situation, maintaining the helping relationship. *The family should set the pace. Only after the family expresses, through their manifestations of recovery of emotional control and readiness to act, that they have understood and assumed the death of their relative, can the coordinator continue with the next phase.*

Recommendation 22.6:

The communication of death should be made by the patient's physician, who will answer any questions the family may have. There is no clear recommendation on how to communicate the death, that is simply stating that the patient has died or that the patient is brain dead

Addressed to: CCU Personnel; Hospital Transplant Coordination

Once the presentations have been made, the communication of the death should be made by the intensivist with the support of the coordinators who, apart from exceptions, will not identify themselves as such at the beginning of the presentations (See Recommendation 22.5)

It is recommended that the communication of death begins with *established communication formulae* similar to "as you already know, the situation of your relative was very serious," "unfortunately we have bad news," or "the situation, unfortunately, has worsened," that give rise to the *communication and explanation of the death*, answering all of the questions asked by the relatives and encouraging, with open questions, the relatives to clarify their doubts.

There is no clear recommendation on whether to communicate the death through a simple statement that the patient has died or stating that the patient is brain dead.

Once the death has been communicated, it is recommended that the coordinators *take charge of the interview, assuming a greater role in the communication with the family, asking about any problems and needs they have and offering the necessary help.* As previously mentioned, the person who has communicated the death can leave the room and attend to other tasks, explaining this to the family.

Recommendation 22.7:

The request for consent for donation should be made clearly, directly and plainly by the coordinator, as an option, a right, a privilege, or a way of helping others. This should always occur after verifying that the family has understood the fact of death

Addressed to: Hospital Transplant Coordination

Before requesting the donation, it is very important for the coordinators *to ensure that the family has understood the fact of death and that they have no other problem or concern that may be interfering with it.* On the contrary, the difficulties should be sounded out through open questions and support, explanations or different ways of approaching the problems (helping relationship) should be offered. As has already been mentioned, the family should set the pace, and only when they have expressed, through their manifestations of recovery of emotional control and action approach, that they have understood and assumed the death of their relative, can the coordinator continue on to the next phase.

The request for donation should be stated *clearly, directly and in plain language. Exaltation of values is important:* the donation should be offered as *an option, right, privilege, or a possibility of helping others.* It is very important to ask what opinion the deceased had (or could have) regarding donation.

Recommendation 22.8:

In the case of a negative response, rejection reversal techniques are recommended. The family shows signs of when the interview is over

Addressed to: Hospital Transplant Coordination

In the case of a negative response, the centers consulted used different techniques::

- Asking the family to express the reasons for the refusal to donate. Once they are expressed, they can be analyzed and appropriately refuted. Solidarity reasons can be used.

- If lack of empathy is observed, the person who is in charge of the interview should be switched and continue to act in a supportive position.

- Give them time, approaching arguments that seem important for the family and maintaining contact, leaving aside the donation, without insisting on it, for some time.

- Identify the persons involved in the refusal to donate and their role within the family, attempting to communicate separately with the negative member, so that this member does not hide and reaffirm in the group and so that the discrepancy can be reduced, everyone assuming the final decision.

It is the family who should set the limit of the interview. The centers consulted state that they stop trying to obtain a donation when the family show signs that *there is no progression, empathy is lost, and/or that they are not receiving any benefit from it.*

Recommendation 22.9:

Regardless of the outcome of the interview, it should end with signs of condolence and affection, maintaining the helping relationship until the final moment

Addressed to: CCU Personnel; Hospital Transplant Coordination

The helping relationship is a benefit for the family that should be maintained until the end.

Recommendation 22.10:

It is recommended that some days later the family should be thanked for the donation through a letter or telephone call

Addressed to: Hospital Transplant Coordination

This makes it possible to formally close the relationship established with the family and generate a positive opinion on the donation.

Recommendation 22.11:

The interviews should be documented and then analyzed, especially the refusals to donate

Addressed to: Hospital Transplant Coordination

Recording the activity performed makes it possible to evaluate the opportunities to improve, since it facilitates the analysis a posteriori of the case and of the possible alternatives to the approach taken. Furthermore, it makes it possible to provoke an educational discussion in the team on ways to respond to the refusal to donate.

RECOMMENDATION 23:

IT IS IMPORTANT FOR THE TEAM INTERVENING IN THE INTERVIEW TO HAVE SPECIFIC TRAINING

Addressed to: Hospital Administration; CCU Responsible Person; CCU Personnel; Hospital Transplant Coordination; Regional Transplant Coordination

It is very important for the persons who participate in the interview to have specific training for the roles they assume. These involve ***elevated difficulty*** and require *specific attitudes*.

Recommendation 23.1:

It is advisable for the medical professional who communicates the death to have training in the techniques of communicating bad news

Addressed to: Hospital Administration; CCU Responsible Person; CCU Medical Professionals; Hospital Transplant Coordination

The teams interviewed consider that training in communication of bad news is essential. If, due to exceptional circumstances, the medical professional

selected does not have this training, the coordination team should carefully prepare the approach to the family, the information that must be given and the way to communicate it (See recommendation 22.1.)

It is important for the co-coordinators to promote specific training of the professionals in the critical care units in these subject matters through courses and seminars held in the hospital.

Recommendation 23.2:

The transplant coordination team should have experience and receive continuing education in all of the aspects related with the interview

Addressed to: Hospital Administration; CCU Responsible Person; CCU Personnel; Hospital Transplant Coordination; Regional Transplant Coordination

The persons who request the consent for donation should be ***transplant coordinators with specific training in donation and transplantation, helping relationship and techniques of communicating bad news.*** In order to renew and update concepts, the personnel of the centers consulted ***periodically receive training***, even if they have previously received this training.

At least one of the coordinators should have ***experience***, which is highly considered by the centers.

Equally, in the centers consulted, the ***active participation of the nursing service*** belonging to the coordination teams in the request is stated. Their skill to develop complicity and to establish a helping relationship with the family in some very difficult moments is recognized.

It is important for the professionals involved to receive specific training in order to avoid the ***emotional overload*** that this type of work may give rise to.

Recommendation 23.3:

There is no clear recommendation on the profile of the cooperator personnel

Addressed to: Hospital Administration; CCU Responsible Person; Hospital Transplant Coordination; Regional Transplant Coordination

Except for one of the hospitals with excellence results in the consent obtaining phase for the donation, the centers do not have their own cooperator personnel. The ideal situation would be for the translator who generally cooperates with the coordinators to receive specific training in donation and transplantation and in the helping relationship, and not be only limited to translating.

RECOMMENDATION 24:

IT IS IMPORTANT TO HAVE RESOURCES TO CARRY OUT THE INTERVIEW

Addressed to: Hospital Administration; Responsible Persons of the Units outside of the CCU; Hospital Transplant Coordination

Recommendation 24.1:

It is recommended to always make the interview in a separate place, with privacy and resources that meet the minimum needs

Addressed to: Hospital Administration; CCU Responsible Person; Responsible Persons of the Units outside of the CCU; Hospital Transplant Coordination

It is important to have privacy to allow the family to express their emotions and freely communicate among themselves and with the interviewers.

It is advisable to have resources that meet the minimum needs (telephone, handkerchiefs, water, some food, etc.)

Some centers consider it important to have several rooms that make it possible to change sites if the coordinator considers it to be necessary. For such effect, they distinguish between the room for information to the family and the mourning room.

It is recommended to conduct the interview in a place where the family is not far from the donor. They may frequently request to see the donor.

Recommendation 24.2:

It is advised to conduct the interview in the morning, with daylight

Addressed to: CCU Medical Professionals; Hospital Transplant Coordination

At this time of the day, they are generally more rested and receptive. However, it is not uncommon for reasons to exist, such as emotional condition of the family, distance, availability of flights, etc., that make it impossible to do so in the morning. In these cases, the situation of the family and the helping relationship established with them come first and the interviews should be made when necessary.

Recommendation 24.3:

If there is other assistance to the family, it is recommended to not use it as an argument to obtain donation or reverse a refusal to donate

Addressed to: Hospital Transplant Coordination

The centers consulted that may offer other assistance to the family, such as transfer of the cadaver or coverage of some of the funeral costs, do not use this argument to obtain consent. This possibility may be commented, when it can be applied, after having obtained consent for donation.

RECOMMENDATION 25

OTHER RECOMMENDATIONS OR SUGGESTIONS

Recommendation 25.1:

It would be desirable to have technical support available on material of interviews, religion, language, etc.

Addressed to: Hospital Transplant Coordination; Regional Transplant Coordination; National Transplant Organization

Without detriment to the training received and to the capacity to respond, the centers consulted consider that it would be convenient to have specific technical support available when there are cultural, linguistic difficulties or others.

Recomendación 25.2:

The helping relationship is a great benefit for the family. It should not only be applied to donation

Addressed to: CCU Personnel, Hospital Transplant Coordination

Some centers consider that the outcome of the helping relationship is positive, and recommend that using it should not be limited only to those cases in which there is a possibility of donation.

Annex I



VII

Benchmarking committee members

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