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Hospital attitude survey on organ donation in the Emilia-Romagna region, Italy

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Abstract The role of hospital staff in the organ procurement process is crucial. Nevertheless, there is little literature about their attitudes toward donation. The Donor Action Hospital Attitude Survey (HAS) comprises a series of questions to assess hospital staff's attitudes, beliefs, and knowledge on organ donation and transplantation. Further analysis of the data will help identify any weak areas in the staff viewpoint and information, highlight potential needs for more education on specific issues, and establish a baseline to monitor future improvements. We used the Donor Action HAS in the Emilia-Romagna region, Italy. The aim of this paper is to assess and better understand the personnel's viewpoint in the 12 main hospitals of the region. The survey was carried out among hospital staff involved in organ donation. 1576 responses were collected (52 % of distributed questionnaires), of which 1024 came from nurses, 475 from physicians, and 77 from other backgrounds. Questions were subdivided into categories, and for every point an overall mark (maximum 3/3) was calculated. Results:

1. Involvement in donation process during the past year: 1.24 /3,
2. Attitudes to organ donation (OD): 2.51 /3,

3. Skills / Self-confidence in donation practices: 1.36 /3,
4. Satisfaction with local transplant coordinator (TC) services: 2.31 /3.

The attitude towards organ donation was positive, 1386 respondents support organ donation. A high percentage (93.6 % of respondents) is of the opinion that transplantation helps save other people's lives. Most uncertainty arises on the question whether donation helps families with grief. It is remarkable that only 53 % of those prepared to donate organs have informed the family of their wish. Many respondents do not feel comfortable performing key tasks close to donation. Major difficulties were observed in explaining to a family the concept of brain death (0.98 /3). Knowledge on the concept of brain-death was one of the most requested subjects for improvement. Emilia-Romagna is the region with one of the highest donation rates in Italy (29.9 pmp in 2000). Nevertheless, more profound knowledge of the local situation could help further improve donation.

Keywords Donor action · Survey · Organ donation · Attitudes

Abbreviations OD Organ donation · TC Transplant coordinator

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Introduction

Donor Action is an international initiative that aims to alleviate organ shortage for transplantation. It was developed by the Eurotransplant Foundation (The Netherlands), Organización Nacional de Trasplantes (Spain) and The Partnership for Organ Donation (USA). The rationale of Donor Action is to increase organ donation with the help of detailed knowledge of the local situation [7]. This information would help identify critical areas in the staff's viewpoint and information, assess the necessary interventions to improve personnel education, and promote organ donation (OD). The perception of OD by the personnel directly involved in the organ procurement process could help narrow the gap between potential- and actual donors. To reach this aim, a hospital attitude survey (HAS) was designed with a series of questions on staff attitudes toward organ donation, toward the level of self-reported confidence in performing a range of donation roles and the satisfaction with the local transplant coordinator (TC). Further analysis of these data can help identify areas of insecurity in the staff's viewpoint and information on organ donation, show on which specific issues more education is necessary, and also gather a baseline to monitor future improvements. Together with the medical record reviews of the deceased patients, this process is an integral part of a hospital's quality improvement around donation and related practices. The purpose of this paper is to find out and analyze the personnel viewpoint in the main hospitals of the Emilia-Romagna region.

Materials and methods

A 32-item multiple choice survey questionnaire translated from the Donor Action Programme, was handed out among 12 hospitals in the Emilia-Romagna region, Italy, between 1998 and 1999. The survey was distributed to all staff working in areas involved in organ procurement and transplantation. The included departments are critical care units, surgery, ophthalmology, trauma, and the emergency departments. Supporting groups of these units, such as legal medicine, pathology, radiology, and social services were also included. The study was organized by the Transplant Reference Center, the regional transplant coordinator of which prepared a meeting at every hospital to introduce the attitude survey. The local transplant coordinator (TC) identified the units taking part, determined the number of questionnaires needed at each hospital, and distributed them. After a deadline, he collected and returned the completed questionnaires to the Transplant Reference Center. A medical doctor directed and analyzed the questionnaires using the specific software provided by the programme. For every point of inquiry, an overall mark was calculated, taking into account the affirmative, dissenting, and not knowing answers. Its maximum value was 3/3 points. We inquired on the following areas:

1. Involvement in the donation process

Respondents had to indicate the number of cases they were involved in during the past year, caring for a potential donor, communicating information on severe brain damage to a family, explaining brain death to a patient's family; requesting organ donation and contacting a TC. Possible answers: 0, 1–3, 4–6 times. Calculated scores: $1 \text{ point} * 0 \text{ time} + 2 \text{ points} * 1\text{--}3 \text{ times} + 3 \text{ points} * 4\text{--}6 \text{ times} / 3 \text{ points}$.

2. Staff attitudes to organ donation

Personnel had to tick the statement that came closest to their belief: they supported organ donation for transplantation; they would donate their own organs/tissues after death; they had informed their family of their wishes regarding donation; OD helped families in grief; OD saved other people's lives. Possible answers: yes, no, don't know (?). Calculated scores: $3 \text{ points} * \% \text{ of "yes"} + 2 \text{ points} * \% \text{ of "?"} + 1 \text{ points} * \% \text{ of "no"}$.

3. Skills/self-confidence level

Questions to evaluate this point were: do you feel comfortable in the following situations: notifying a TC when a potential donor is identified; explaining brain death to a family; introducing the subject of OD; asking a family to make a decision regarding OD; comforting grieving families. Possible answers: yes, no, don't know (?). Calculated scores: $3 \text{ points} * \text{numbers of "yes"} / \text{numbers of "yes"} + \text{numbers of "no"}$

4. Satisfaction with services provided by the local TC

Respondents had to indicate how satisfied they were with the services provided by the TC in the past year in the following areas: coordinating the donation process; managing the clinical aspects of donation; making the donation request; hospital education on OD. Possible answers: yes, no, don't know (?). Calculated scores: $3 \text{ points} * \text{numbers of "yes"} / \text{numbers of "yes"} + \text{numbers of "no"}$

5. Knowledge on organ shortage

This was evaluated through the following questions: state the amount of people nation-wide waiting for an organ; state the percentage that would eventually receive an organ. Furthermore, the question was asked whether brain death was a valid determination of death. No score was calculated.

6. Disposition towards education in donation issues

Respondents were asked if they received or would like to receive training in any of the following areas: clinical management of donors; coordinating the OD process; family grief counselling; brain death; making the donation request; family issues in decision making. No mark was calculated.

Statistical analysis was made using the Statistical Package for the Social Sciences software (SPSS). Significance of the bivariate analyses was evaluated by means of cross tabulations with Pearson's chi-square test. Probability values at $P < 0.05$ were considered statistically significant.

Fig. 1 Overall respondents by profession

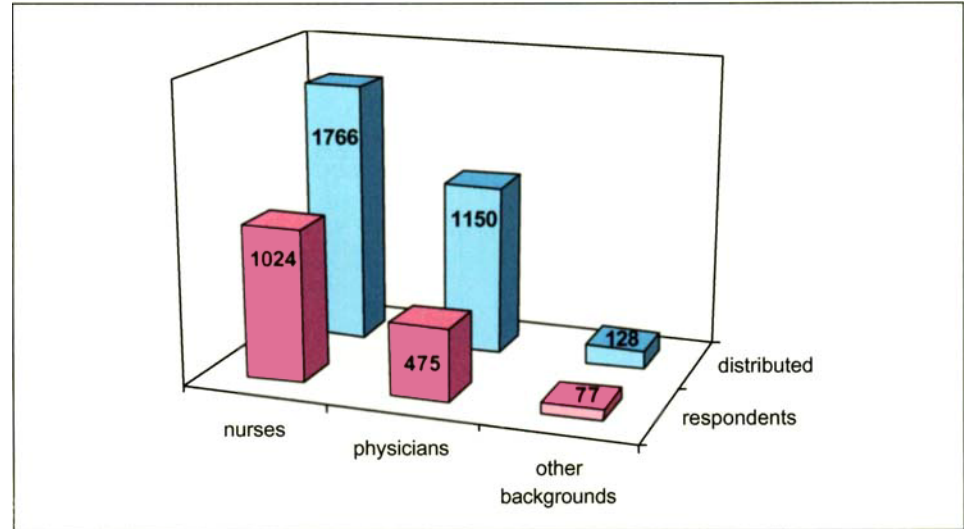
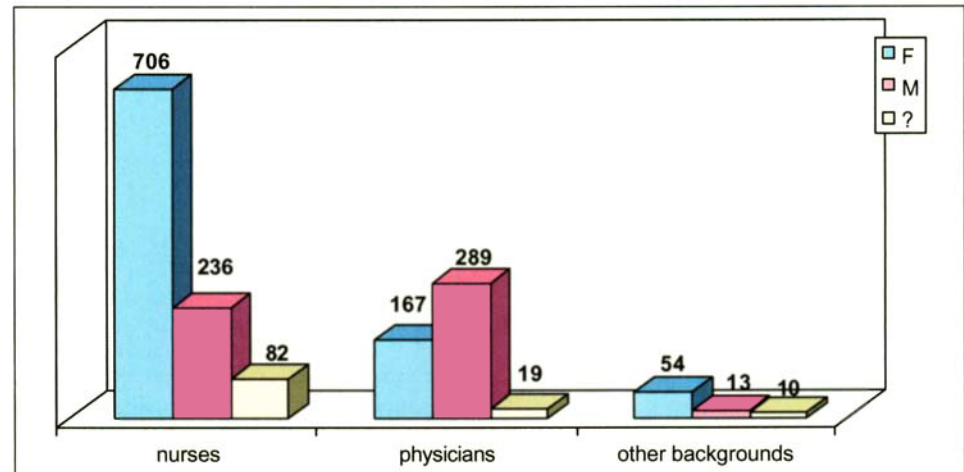


Fig. 2 Overall respondents by gender



Results

A total of 3044 anonymous questionnaires were distributed, divided as follows: 1766 (58%) nurses, 1150 (38%) physicians, and 128 (4%) other backgrounds. Of these, 1576 (52%) were returned. Of the nurses, 1024 (58%) returned their questionnaires; of the physicians, 475 (41%); returns from other backgrounds amounted to 77 (60%) (Fig. 1).

The overall male/female distribution of the respondents was 34%/59%, with 7% of unknown gender (Fig. 2).

Age distribution was 44 (3%) under 25 years of age; 583 (37%) from 25–34 years; 533 (34%) 35–44 years; 280 (18%) 45–54 years; 50 (3%) over 54 years old; and 86 (5%) did not answer (Fig. 3).

Working experience in years at the present unit was: 158 (10%) less than 1 year; 447 (28%) 1–5 years; 407

(26%) 6–10 years; 280 (18%) 11–20 years; 190 (12%) more than 20 years; and 94 (6%) did not specify (Fig. 4).

The questions were subdivided into categories

Involvement in the donation process during the past year

Overall mark 1.24/3. The majority of respondents (81%), even if working in departments involved in donation-transplantation activity, were not directly involved in the donation process, whilst 14% of respondents were involved in between 1–3 cases in the organ procurement process, and only 5% of them 4–6 times. (Fig. 5 and Table 1)

Fig.3 Overall respondents by age

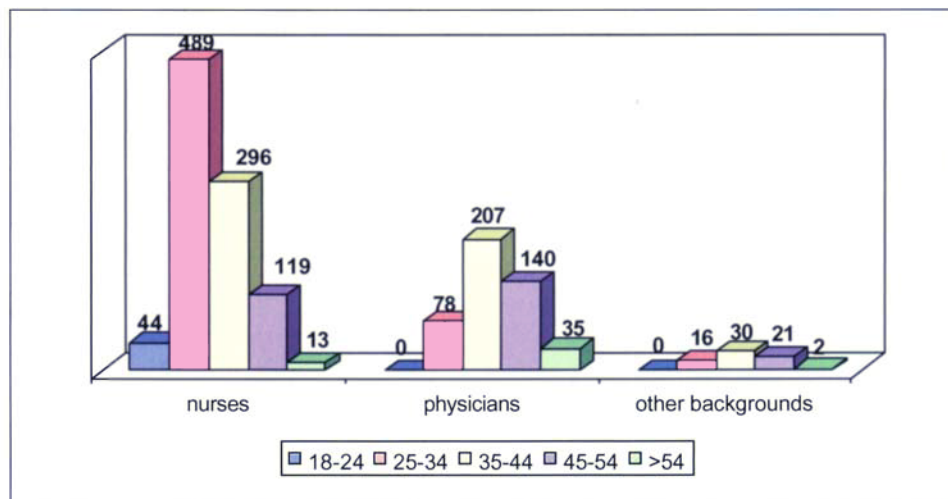


Fig.4 Overall respondents by experience (years) in organ donation and/or transplantation departments

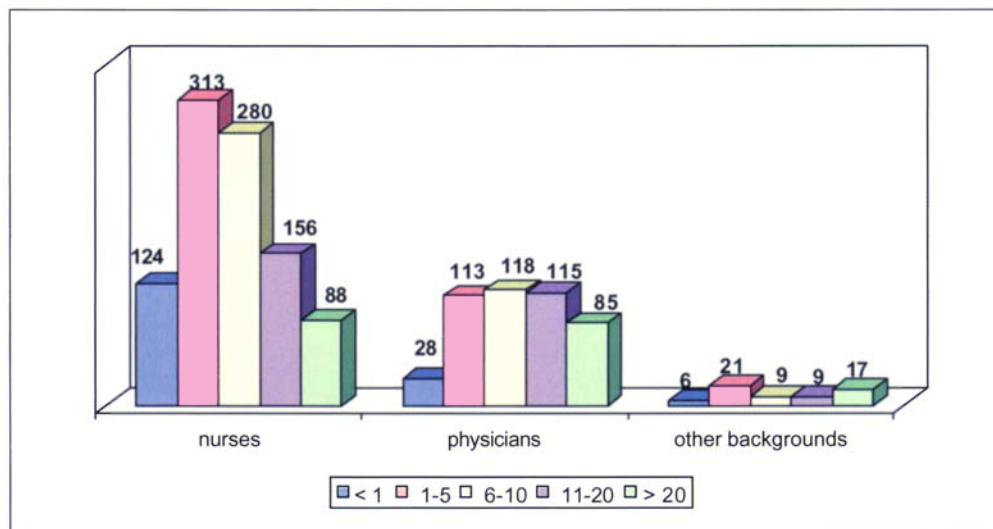


Fig.5 Involvement in organ donation process during past year

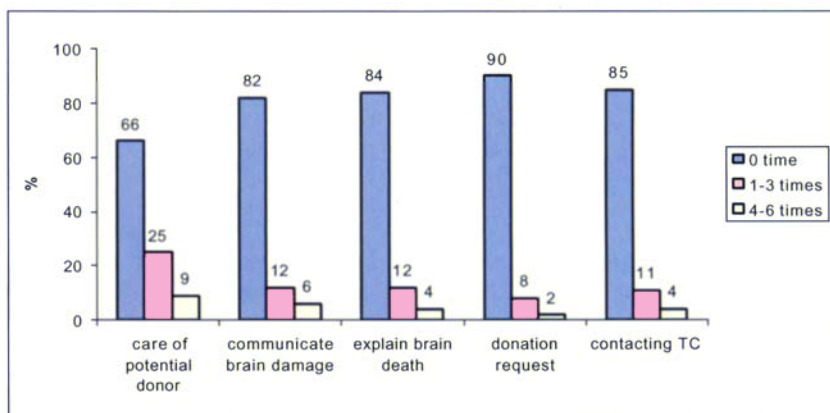


Table 1 Involvement in organ donation process during past year (by profession subgroups)

Involvement in donation practices in past year (number of cases / respondents)

Profession	0 Time	1–3 Times	4–6 Times
Physicians	67 % (294/437)	23 % (99/437)	10 % (44/437)
Nurses	87 % (757/864)	10 % (84/864)	3 % (23/864)
Other backgrounds	94 % (38/41)	4 % (2/41)	2 % (1/41)
Total	81 % (1090/1342)	14 % (185/1342)	5 % (68/1342)

Table 2 Staff attitudes to organ donation (by profession subgroups)

Attitudes towards OD % (Number of positive answers / total respondents)

Profession	Support donation	Would donate own organs	Would donate own tissues	Told family of wishes	Would donate family organs (adult)	Would donate family organs (child)
Physicians	96 % (451/471) ^a	85 % (399/471) ^b	87 % (374/432) ^c	54 % (252/471)	81 % (383/473)	61 % (288/473)
Nurses	86 % (876/1017) ^a	75 % (760/1017) ^b	74 % (675/914) ^c	54 % (545/1010)	77 % (787/1017)	49 % (491/1009)
Other backgrounds	79 % (59/75)	65 % (49/75)	63 % (40/64)	40 % (29/72)	64 % (48/75)	31 % (22/72)
Total	89 % (1386/1563)	77 % (1208/1563)	77 % (1089/1410)	53 % (826/1553)	78 % (1218/1565)	51 % (801/1554)

^a $P < 0.001$ ^b $P < 0.0001$ ^c $P < 0.0001$

Attitude to organ donation

Overall score 2.51/3. In favor of organ donation were 96 % physicians, 86 % nurses, and 82 % from other backgrounds ($P < 0.001$). These percentages decrease to 85 % for physicians, 76 % for nurses, and 69 % for others, when asked about their willingness to donate their own organs ($P < 0.0001$). A slight trend towards a decrease in supporting organ donation was observed with the rise in age throughout all professional categories. The proportion between the intention to donate adult and child relative organs was 84 % versus 52 %, with a high percentage of not knowing answers (38 %), when asked about descendants. Interestingly, even if 78 % were willing to donate their own organs, only 53 % of them had informed their family of this wish. This percentage remains the same for all profession- and age subgroups. (Fig. 6 and Table 2).

Skills/Self-confidence in donation activities

Overall score 1.36/3. The highest comfort levels were attained when notifying the TC (61 %) and supporting a family (50 %), the lowest level of self-confidence was reached when requesting donation (32 %) and explaining brain death (31 %). As expected, skills levels were higher for physicians in all the items inquired (Fig. 7 and Table 3)

Satisfaction with local transplant coordinator (TC) services

Overall score 2.31 /3. Overall, the respondents reported satisfaction with the services provided by the transplant co-ordinators. However, while there was high satisfaction for the coordinating aspects (54 %), there was less

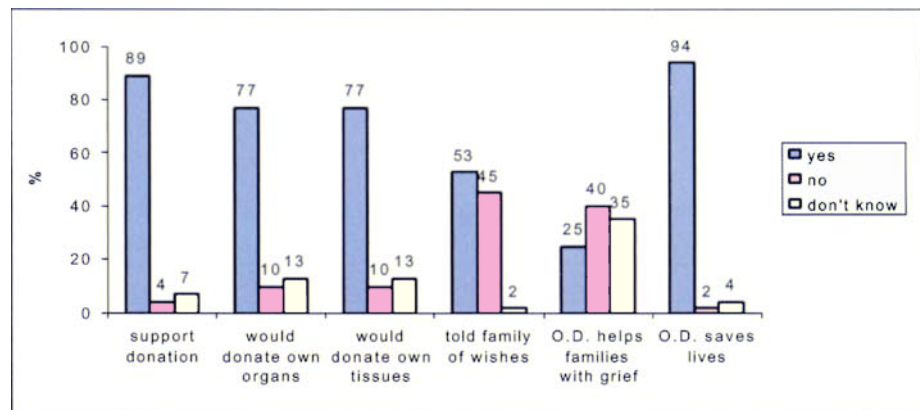
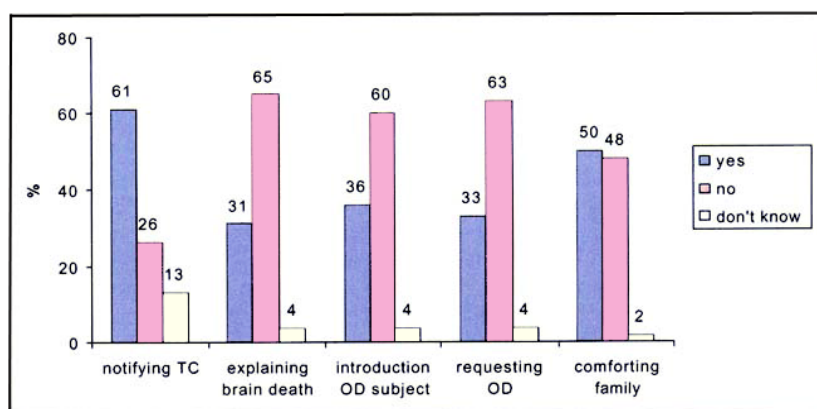
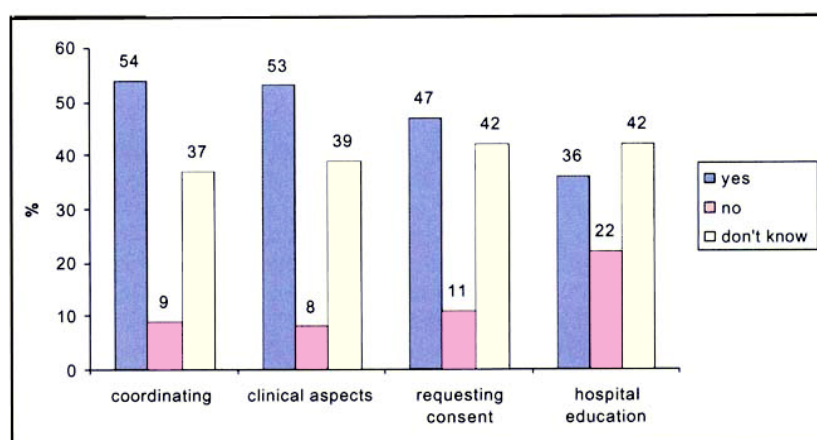
Fig. 6 Staff attitudes to organ donation

Fig. 7 Skills / Self confidence in donation practices**Fig. 8** Satisfaction with transplant coordinator services

satisfaction with the hospital education (36%). We must consider the high percentage of *not applicable* answers (45%). (Fig. 8 and Table 4)

with the concept of brain death. It was found that 2.8 % disagreed, 5.5 % answered that they did not know.

Knowledge on organ shortage

Only 25 % of physicians and 23 % of nurses answered the question on the number of patients waiting for transplantation correctly. Brain death was deemed a valid definition of death by 1174 (76.7 %), 103 (6.7 %) disagreed, 252 (16.4 %) did not know, and 47 (3 %) did not answer. Interestingly, not all the physicians agreed

Requests for education in donation issues

Courses on organ procurement were participated in by 7 %; 43 % stated they would like to participate; 50 % did not answer. The training priorities were: coordination of the organ donation process, the brain death concept, and clinical management of the donor. In this sample, the preferred type of training was formal educational sessions rather than informal meetings.

Table 3 Skills / self confidence in donation practices (by profession subgroups)

Comfort level with the following situations % (Number of positive answers / total respondents)

Profession	Notifying TC	Explaining brain death	Introducing OD subject	Requesting OD	Comforting family
Physicians	77 % (334/433)	56 % (240/432)	51 % (221/430)	48 % (208/434)	55 % (238/434)
Nurses	53 % (439/825)	19 % (160/830)	30 % (247/833)	26 % (214/833)	47 % (405/854)
Other backgrounds	56 % (23/41)	21 % (9/42)	20 % (8/41)	26 % (11/43)	54 % (25/46)
Total	61 % (796/1299)	31 % (409/1304)	36 % (476/1304)	33 % (433/1310)	50 % (668/1334)

Table 4 Satisfaction with transplant coordinator services (by profession subgroups)

Satisfaction with TC services % (Number of positive answers / total respondents)					
Profession	Coordinating	Clinical aspects	Requesting consent	Hospital education	Overall responsiveness
Physicians	61 % (234/382)	61 % (228/375)	54 % (201/374)	46 % (170/372)	44 % (163/370)
Nurses	49 % (283/579)	48 % (267/561)	42 % (234/553)	30 % (174/580)	34 % (188/552)
Other backgrounds	45 % (10/22)	52 % (12/23)	36 % (9/25)	44 % (11/25)	40 % (10/25)
Total	54 % (527/983)	53 % (507/959)	47 % (444/952)	36 % (355/977)	38 % (361/947)

Discussion

The consolidated hospital attitude survey is based on 1576 interviewees in the 12 largest hospitals of the Emilia-Romagna Region. These 1575 interviews represent 52 % of the questionnaires distributed to all people working in departments involved in the donation-transplantation activity. The percentage of respondents is an acceptable response rate. Other similar studies reflected overall response rates between 35–50 % [9, 12]. Ideally, a survey such as the HAS survey requires a minimum return of 40 % to achieve a reasonable level of confidence in the results [6]. The survey shows little direct staff involvement in any aspect of the organ donation process. Only 14 % of respondents, even of those working in critical areas, were involved, in between 1–3 cases, in situations calling for the care for a potential donor, contacting the transplant coordinator, delivering the news of the brain-death of a family member to the bereaved, or requesting consent for organ donation. An even lower percentage (5 %) was involved in this process 4 to 6 times.

As is to be expected from people well informed of the transplantation procedure, there was a high level of support for organ donation from this group. A high percentage (93.6 %) of the respondents state that transplantation helps to save other people's lives. Most uncertainty prevails on whether donation helps families to cope with grief. Only 25.5 % gave affirmative answers to this question. Of all respondents, 88.6 % supported organ donation, but it is notable that when they were asked about their willingness to donate organs and tissues of their own, the positive answers diminished to 77.2 %. This caution could be linked to incomplete knowledge on brain death and organ donation, but also to the refusal to consider one's own death. In contrast with other studies [9, 16], the willingness to donate the organs of a close relative was higher (84.0 %) than to donate one's own organs; 6.2 % stated readiness to donate the organs of a next of kin, even against the deceased's wish.

We found some differences among professional subgroups. However, Physicians seemed to be more sensitive to this subject, and this could be related to better knowledge of organ procurement procedures. Here we found no difference between the willingness to donate

one's own organs or tissues. On the contrary, the difference between the intention to donate adult- and child relative organs was 78 versus 51 %, with a high percentage (38 %) of respondents who had not decided whether or not to donate when asked about descendants. The psychological reasons of this lack of decisiveness should be applied to the mind's refusal to accept the death of a child.

Regarding the lack of discussion on organ donation in the family, we confirmed the results of other studies [1, 12]. Only 53 % of our responders had informed their family of their willingness to donate. In consequence, the wish of the deceased could not be guiding the decision concerning organ donation. The reason of this lack of communication is again to be found in the fear of death and in the consequent refusal to talk about this issue with relatives. During information campaigns, it is necessary to emphasize the importance of communicating this wish. Usually, a potential donor dies unexpectedly, and in such a situations it is difficult for the family to make a decision without knowing the deceased's wish. The American Medical Association's Council on Ethical and Judicial Affairs concluded: "the individual's interest in controlling the disposition of his or her own body and property after death suggests that it is ethically preferable for the individual, rather than the family, to decide to donate organs" [4]. Since 1999, a new transplantation law in Italy [10] establishes the concept of informed presumed consent. With the aim of knowing everybody's wish concerning donation, a donor card was sent to every inhabitant over 18 years of age. This initiative had two purposes, the first was to enable the people to state their wish, and the second was to promote discussion in the family. In this way, we hope to raise donation willingness in our country in a few years.

Self-confidence in organ donation practices was evaluated by asking questions on the level of comfort experienced in dealing with diverse situations in donation-related tasks. The overall score was below average (1.36/3). But this point was seen to be not proportional to real skills. Comparing the results of HAS in other countries, we found in Spanish respondents, who show the highest donation rate, the lowest rate of staff preparedness. This is supposed to be correlated to an integration of the role specialisation in donation activity into hospital practice [18].

As regards satisfaction with the services provided by the transplant co-ordinators, respondents reported different answers according to the TC roles. While there was high satisfaction for the coordinational (54%) and clinical (53%) aspects of the role, there was less satisfaction with the hospital education provided by the TC (36%). Higher support for the TC was observed among the physicians than among the nurses. We must also consider the high percentage of *not applicable* answers (45%). Unfortunately, in many cases, the TC figure was unknown to other hospital colleagues, even among people potentially involved in donation-transplantation activity.

Knowledge on organ shortage was evaluated by asking the proband to state the amount of people nationwide waiting to receive an organ, and the percentage that would eventually receive one. Only 22% of the respondents answered correctly. This suggests that it is necessary to improve general information on organ transplantation. The point is further stressed by the major request (223 persons) for improved information through mass media, schools and universities, stated in the comment section. When asked about their educational needs, overall the respondents viewed coordinating the donation process in the hospital, the concept of brain death, and clinical management of the donor as training priorities.

Otherwise, it was unexpected to find that not all physicians, in spite of their professional background and fact that they were working in transplantation areas, agreed with the concept of brain death (2.8% disagreed and 5.5% did not know). Although the Harvard Com-

mittee established criteria for the determination of brain death in 1968 [2], diagnosis and certification of brain death remain a non-uniform practice [3, 8, 11, 15]. Whole-brain criteria for death are advocated in most countries, though some, The United Kingdom, for example, accept the absence of brain stem function as equivalent to a patient's death [5, 13, 14]. These differences regarding standards and procedures, and even the personnel involved in brain-death certification could be the cause of our findings on the acceptance of the brain death concept. As observed in other studies [17], information strategies must be emphasized not only for the community, but also among hospital staff, especially when involved in OD practices.

Emilia-Romagna is a region with one of the highest donation rates in Italy (29.9 pmp in 2000). We believe that this potential can further be increased. Knowledge of the local situation through a detailed analysis of a staff survey could be the first step, allowing the development of customised protocols and targeted educational opportunities for individual hospitals and units.

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