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Evaluation of the quality of the communication and emotional support during the donation procedure: The use of the donor family questionnaire (DFQ)

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ABSTRACT

Purpose: A multi-centric study in Intensive Care units (ICU) and Emergency departments (ED) was designed to evaluate whether the provided communication and emotional support to the family in the context of organ donation met the international recommendations of the European Donor Hospital Education Program (EDHEP).
Materials and methods: Using a participatory approach and focus groups, a questionnaire was constructed: Donor Family questionnaire (DFQ). The questionnaire was distributed to 203 families. The data were analysed on item level.
Results: Sixty-four families participated, and 89% considered the communication as tactful. Only 24.1% had a separate conversation about passing and donation, which is the recommendation. 88.5% reported they could count on emotional support in the first phase on the ICU/ED. This dropped during the parting phase and the aftercare. The physician is perceived as the most active caregiver in the emotional support during the entire procedure.
Conclusions: The DFQ is a useful instrument to evaluate the donor procedure. The physician is important in the first phases of the donor procedure for the medical explanation. Other disciplines could be more involved in the following phases to assure enough emotional support, but this issue requires further exploration.

1. Introduction

Organ transplantation is a key treatment for end-stage organ dysfunction of kidneys, liver, heart and lungs. The success of these surgical interventions is until today depended upon organ donation. The shortage of organs all over the world has inspired caregivers and researchers to improve the donor procedure [1-7]. A lot of initiatives has been taken to sensitize communities [7-15], and specific laws have been developed to allow the procedure to proceed more smoothly. The opting out system where every citizen is a potential donor, unless there is a formally registered refusal, seems to be working effectively and generates most donors. In Belgium, using this opting out system, the rate of organ donation is one of the highest in Europe. Nevertheless, the waiting list is still growing and each year between 80 and 120 patients still die while waiting for an organ.

In Belgium, 43% of the potential donor pool is used. Of the 57% donors not used: 36.4% are not eligible due to medical contraindications, 14.2% due to family refusals, 2.3% due to registered donor refusals and the rest is unknown (data from Belgian Transplant Society). In previous studies on the donor procedures at the Intensive Care Units (ICU) and Emergency Departments (ED), communication about end of life and organ donation with the family has been seen as a central factor influencing the donation process [16-21]. To evaluate the way the communication is within a donation procedure, it is necessary to rely on family members experiences [22,23]. It is shown that investing in training of the communication skills regarding emotional support is related to a higher donation consent [12,24,25]. Several studies showed the request for donation came as a surprise and was emotionally overwhelming. Most family members expressed an overall satisfaction with the information provided at the time. The possibility to say good-bye was perceived as very important [15]. This has led to international recommendations on the communication about the procedure, distributed by the European Donor Hospital Education Program (EDHEP) courses for doctors and nurses [16,26-28].

The main goal of this study was to evaluate the communication and emotional support provided to the donor families in the Belgian ICU's and ED's in order to improve common procedures. We focused on: 1. experiences during the donor's hospitalization, 2. experiences about the

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communication, and 3. experienced emotional support during the different phases of the donation process.

In order to makes comparisons between different centres or countries, the use of a standardized questionnaire may be appropriate. However, such instruments are lacking. Therefore, another aim of this study was to develop and introduce a new questionnaire. In particular we describe the construction and content validation of this questionnaire. Subsequently, we describe some results obtained by this questionnaire.

2. Methods

2.1. Procedure

This study was the initiative of the Transplant Society of Belgium, section transplant coordinators. This section represents the transplant coordinators of the 7 transplantation university hospitals in Belgium. A 'transplantation coordinator' coordinates the process of organ allocation and retrieval and is a specialized nurse. 'Donor coordinators' are ICU physicians and/or ICU nurses in the local and university hospitals who have the specific task of supervising the donation processes. In our survey which aims to collect information on the experiences of the families at the ICU and ED, we have considered the donor and transplantation coordinators as one group of caregivers specialized in organ donation.

The study was approved by the Ethical committee of the 7 participating hospitals with the University Hospital of Leuven as principal investigator. We (University Hospital of Ghent) have the consent and agreement of the principal investigator to publish the results of our own centre and its 17 partner donor hospitals.

A questionnaire was designed and distributed by the transplant coordinators of the 7 research hospitals to 1500 Belgian family members of organ donors between 2009 en 2014. In order to respect a bereavement period, the questionnaires were sent out minimum 1 year after donation. Informed consent for the study was given by participating, this was mentioned in the cover letter. The goal in this study was to focus on the experiences of the group of families who consented to organ donation; donors after brain death and donors after circulatory death. Other inclusion criteria were: older than 18 years, knowledge of the Dutch or French language.

2.2. Participants

We sent out 203 questionnaires. All families received a questionnaire by mail. A cover letter mentioned that in the event of more than one family member would like to participate, an extra questionnaire could be requested. None made use of this possibility. Of the 203 questionnaires 4 returned because of a wrong address. Sixty-four of 199 relatives participated in the study, which represents a response rate of 32% (Fig. 1: Flow chart). There was a multicentre agreement that no reminders were sent to complete the questionnaire.

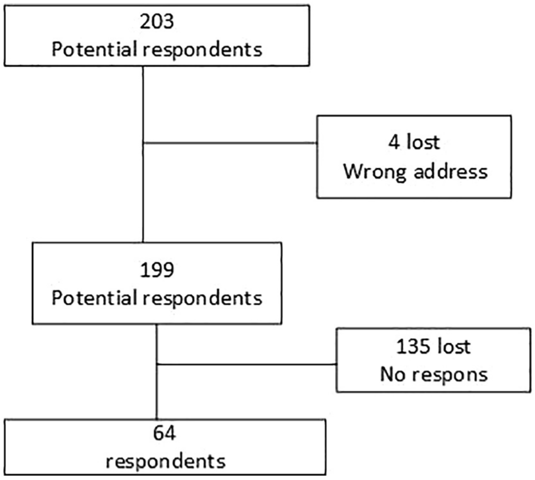

Fig. 1. Flow chart.

Socio-demographic characteristics of the participants are presented in Table 1.

2.3. Development of survey: construction of the donor family questionnaire (DFQ) based on a participatory approach

2.3.1. Processing the literature review and conducting a first draft of the questionnaire

The purpose of the questionnaire is to evaluate how donor families experience the communication and support during the donation process. First, a brainstorm session was organized including transplantation/donor coordinators of the transplantation hospitals in Belgium (Leuven, Antwerp, Liège, Ghent and 3 in Brussels) and a psychologist of the University of Leuven. In that session the constructs and possible items were discussed. Second, a literature search was performed. The PubMed and Science of Knowledge databases were used with the keywords: donation, family, questionnaire. By deductive procedure, the information is converted to the time frame of the donor procedure with 5 basic phases and taking into account the international recommendations of the EDHEP [26]. Third, a draft of the questionnaire was developed. It consisted of 5 clusters. The *first cluster* 'care in the ED and ICU' assessed satisfaction with care, sufficient information, quantity of the conversations, tactfulness of the conversations, emotional support. The *second cluster* 'communication about passing/brain death/ending therapy' assessed where, tactfulness, room for questions, emotional support, time spend. The *third cluster* 'saying goodbye' assessed sufficient time, separate, emotional support. The *fourth cluster* 'communication about organ donation' assessed tactfulness, information, time to decide, where, possibility for a second conversation, liberty to differentiate in the donation, known opinion of the deceased, compromise in the family, concerns about the body after donation, concerns about the opportunity to say goodbye. The *fifth cluster* 'aftercare' assessed to be informed, who was involved, information about the donation and the recipients, the wish to receive a letter of the recipient, information about organizations for donation families, regretting the donation, influence on bereavement process. In constructing items, we aimed for short sentences, neutral questioning and avoiding double negation. As much as possible multiple-choice questions were used and a 4-point Likert scale.

2.3.2. The final version of the DFQ using a participatory approach as validation procedure

The finalization of the questionnaire *Donor Family Questionnaire (DFQ)* was realized through a collaboration between two psychologists of the university hospitals of Leuven and Ghent. The Ghent Health Psychology lab was asked for advice and support. In line with the

Table 1
Socio-demographic characteristics of the participants.

Gender	*n* (%)
Male	35 (55%)
Female	28 (44%)
Age	years
Median	50
Range	24–83
Relationship to donor	*n* (%)
Spouse	23 (35.9%)
Parent	15 (23.4%)
Child	18 (28.4%)
Sibling	7 (10.9%)
Unknown	1 (1.6%)
Work or school situation	*n* (%)
Working	47 (68.8%)
Retired	16 (25%)
Student	1 (1.6%)

recommendations of Brod et al. (2009) on content validation, we started up a process to ensure "whether items are comprehensive and adequately reflect the patient perspective for the population of interest" ([29] page 1263). Feedback on DFQ in terms of its relevance of the topics and clusters, the form and comprehensibility of the items was obtained from domain experts, stakeholders and experts in donation and transplantation, family representatives

First, *feedback of domain experts:* The draft questionnaire was evaluated at the meeting of the Society of Intensive Care Medicine and the meeting of the the transplantation/donor coordinators of the Belgian Transplant Society. The suggestions made were incorporated in a second draft. Second, *feedback of stakeholders and experts in the field of donation and transplantation: the second draft was distributed by email, the received feedback was* integrated in the third draft of the questionnaire. Experts and stakeholders who evaluated the draft were: 4 doctors and 4 nurses of the ICU of the university hospitals of Leuven and Ghent, 4 psychologists working in transplantation and donation context, 4 transplantation and/or donor coordinators, 2 'Eurotransplant organization' board members, 4 board members of an association for donor families 'NAVADO', 2 pastoral workers and an 1 psychologist expert in the field of bereavement. Third, *feedback of two focus groups with 7 donor family representatives:* 10 persons were invited by a transplantation coordinator of the Ghent University Hospital to provide their feedback on the second draft of the questionnaire. Seven participated, 2 did not show up, and 1 refused because it was too emotional. Two psychologists (of the university hospitals of Leuven and Ghent) moderated the focus groups. Individual screening of the draft by each family member was followed by a group discussion on the proposed changes in order to come to a compromise. Their feedback was collected and incorporated in a final version of the DFQ. For example,: most items are given an open space to give a comment, an explicit request from the family members.

The DFQ consists of 35 items and 4 sub-items: for 16 items a 4-point Likert scale was used ranging from 1 "totally agree" to 4 "disagree", 12 items "yes" or "no", 5 multiple choice items with response possibility "too much", "enough", "too little" and 2 multiple choice items with specific response possibilities. In total 5 multiple choice questions to indicate which healthcare provider did give emotional support: medicine, nurse, social worker, psychologist, pastor, donor coordinator, other, don't remember anymore. (DFQ: see Appendix A).

2.4. Statistical analyses

The study aimed to document the experiences on experiences during the donor's hospitalization, communication and emotional support of the families in the donation process. Therefore descriptive statistics (frequencies, percentages) were used to summarize the responses to each item of the DFQ as a function of the three topics.

Mann-Whitney *U* test and Kruskal-Wallis-test was performed to evaluate differences in the experiences among groups based on gender; age categories (≤ 50 $n = 32$, >50 $n = 31$), and the relationship to the donor (spouse, child and parents).

Fisher's exact test and chi-square test were performed to determine correlations between item scores and significance (<0.05).

For all analyses SPSS, Version 25 was used.

3. Results

We first looked for differences in response based on gender, age or relationship with the donor.

The comparisons between the groups did not reveal significant ($p < .05$) differences in their response on the different items. There was a borderline significant difference between gender of respondent on the experience 'The information about the condition of my loved one was given in a tactful manner' in the hospitalization phase ($p = .05$). Approximately 10% more men found the information was tactfully given.

Here, we briefly review some results of the item scores (DFQ in Appendix A), we focused on experiences regarding three different topics during the donor process: 1. the donor's hospitalization, 2. communication and 3. emotional support.

3.1. Experiences during the donor's hospitalization

All respondents (100%) agreed that their family member was well taken care of. None of them reported that they had too many conversations to talk about the medical condition of the loved one, 24.2% found they had too little conversations.

89% felt the information about the medical condition was given tactfully, in 37.9% the initiative came from the health care provider.

3.2. Experiences about the communication, according to the international recommendations of European Donor Hospital Education Program (EDHEP) [16,26-28]

3.2.1. The conversation about the death/ending therapy must be separated from the conversation about donation

Almost all respondents reported that the caregiver delivered the conversation about the passing/brain death/ending therapy tactfully (92.1%) and confirmed that they could ask questions (91.4%), 15.9% respondents found that the caregivers did not take sufficient time for this conversation.

The conversation about donation took mostly (80.6%) place in a separate room. Donation was communicated to 48 families while in the ICU, to 13 families in the ED and to 3 families somewhere else. Forty-four (75.9%) respondents said the donation conversation was not separated from the news about the passing, brain death and ending therapy of the relative, referred to in the questionnaire as 'bad news'. A family member who added a comment wrote: *"The request for organ donation came too soon".*

Fifty-seven (89%) respondents said the conversation about the donation was tactful.

3.2.2. The relatives must receive enough information

79.4% felt they had enough information. Thirteen respondents felt they received too little information. Respondents with regrets about their decision, did not report significantly receiving more or less information about the donation ($p < .11$) than respondents with no regrets. Thirty-four (54.8%) of the participants reported there was no second conversation offered to listen to doubts or questions. Three participants brought up the organ donation themselves, for 46 the caregiver brought it up. The relatives who initiated the donation conversation did not report receiving significantly more or less information ($p < .47$) as compared to the relatives who did not initiate the conversation.

Almost all families (91.9%) reported they wish to have information about the condition of the acceptors after the donation and 85.7% want to receive this information permanently, 72.9% of them would like to receive a letter from the acceptors.

Information of the self-care group of donor families was appreciated by 58.6%.

3.2.3. The relatives must receive enough time to make a well thought decision

78% of the participants report to have got sufficient time to think it over. The respondents with regrets about their decision, did not report significantly more or less time to decide ($p < .12$). Thirteen persons reported too little time to make a decision. Thirty-one participants (35%) were concerned they would not see the family members' corps after the organ procurement and said they were concerned about mutilation of the corps (49.2%). Some of the families shared their concerns as such: *"I was concerned I was not going to be able to have a physical send-off" "I was worried, especially of how the face would look like afterwards".* According to 91.8% of the families, the decision of donating was theirs to make, also the decision of which organs were to be donated (80.9%). In 39.1% of the family's organ donation had been discussed earlier before the death of the beloved occurred. Only 26.7% of the relatives knew the deceased wish to donate. Some families reported a dispute between family members (17.2%). Some respondents added this information: *"It was about my sons hart. My husband didn't feel comfortable with the feeling of burying our son without a heart", "My ex was against donation"*. The relatives who initiated the donation conversation reported to receive comparable time to make a decision ($p < 1.00$) as the relatives who did not initiate the conversation. 95.3% of the relatives had no regret of the donation. Some of them explained it by: *"It gives me comfort to know my son lives on in someone else", "This decision saved a life and his death was meaningful", "'I am satisfied to have helped others"*. Our study found no significant association between the time to think it over, amount of time to part and having regrets about the donation decisions. The time to think it over was perceived to be too little for those who regret their consent. The respondents with regrets wrote: *"It is too early to say. The pain of my loss in unbearable", "I still do question my decision if it was the right thing to do. I doubt if his death was 100% certain, because if it was not, then I have made a terrible mistake", "I was not able to make a thoughtful decision at that moment".*

3.3. Experiences about receiving emotional support

An average of 78.2% participants felt emotional supported during the different phases. We found no significant relationship between the experienced emotional support and more or less information, time given to decide, having regrets about the donation decision. 84.4% of the relatives confirmed the caregivers gave them enough time to part from their family member with enough privacy. Also, no significant association was found between the amount of time received to say goodbye and having regrets about the donation decision ($p = .06$). 50.8% relatives said they did not have received information about the possibility to see the beloved after organ procurement. A participant who did not knew about this and was not able to see the beloved after surgery commented: *"It was a pity I could not do this"*. Twenty-seven of the 33 respondents felt the visit of the corps after de procurement as a positive experience, while 3 felt it as a negative. Family members who saw their family member after the surgery shared their feelings about this incident as: "*I had mixed feelings about this, on one hand he saved a life and on the other hand, seeing him like that was very painful and confronted me that he was really dead", "I needed the final goodbye to be physical and I was glad this was possible after the surgery", "He wasn't shaved, his hair was not combed, and he did not seem neat".*

We found a significant difference ($p < .04$) concerning time given to say goodbye in the group who initiated the donation topic and the group who did not. 91.3% of the respondents who did not initiated the conversation on donation said they received enough time, 33.3% of those who initiated the conversation by themselves said they had enough time. Concerning the emotional support during the parting process ($p < .25$) or aftercare ($p < .09$), no significant difference was found between relatives who initiated the conversation about donation and those who did not.

Throughout the different phases of the donation process between 72.1% to 88.5% of the families reported to have been emotionally supported (Table 2).

At the question '*From who did you receive emotional support?*' the families perceived the physician as the most supportive caregiver during most phases of the procedure: hospitalization phase (67.2%), conversations about the passing/brain death/ending therapy (59.4%), aftercare (28.1%). In the parting process the nurses was more frequently endorsed as providing emotional support (46.9%). In the aftercare the donor coordinator gives as much support as the doctors.

Psychologists have a limited presence in the donation process, they were almost equal present in the hospitalization (17.2%) as parting phase (18.8%), less in the bad news conversations (9.4%) and aftercare (14.1%) (Fig.2).

4. Discussion

This paper describes the development of the Donor Family Questionnaire (DFQ), and reported the experience of donor families on the communication and emotional support within the donor procedure at ICU's and ED's of the Ghent University Hospital in Belgium and its partner hospitals. During the development various stakeholders were involved and several steps were taken to guarantee content validity. Both donor families and health care providers were involved and provided feedback in the process of construction of the DFQ. There was a great uniformity in the received comments. Some of these comments were: changes regarding design, formulation of the questions and request of open spaces for extra information. There were no comments about item content.

We believe that our tool can evaluate the communication and emotional support given during the donation process (as supported by the EDHEP) and may encourage regular evaluation of this crucial aspect in donation. The questionnaire may also contribute to a better service and may possibly have a spin-off on the limitation of the family refusals. A Dutch, French and English version is available (English version at the end of this article). More studies will be needed to confirm the reliability, validity and usefulness of this questionnaire.

Overall, the evaluation of the communication and provided emotional support during the donor procedure was positive. All participants were satisfied about the given care during *the donor's hospitalization* and almost every one found that the provided information was enough. A quarter of them would have preferred more conversations about the condition of their relative. This might be related to the worries the families had about the evolution and a need for reassurance. It also could be that the participants only take into account the conversations of the physicians as we have seen they perceive them as most active caregiver in the whole process. Studies show that the physician takes the lead in the conversations with the family and nurses mostly do not actively take part in the conversations. However they wish to participate in these meetings in order to be well informed for the follow-up contacts with the family [30]. Families perceived that in more than half of the time the initiative for a conversation came from them. None of the families reported they had too many conversations, but some did mention to little, which might indicate that caregivers have to stay attentive for

Table 2
Frequencies of emotional support perceived in the different phases.

	Totally agree, *n* (%)	Somewhat agree, *n* (%)	Somewhat not agree, *n* (%)	Not at all agree, *n* (%)
During the donors hospitalization ($n = 61$)	36 (59%)	18 (29.5%) 88.5%	7 (11.5%)	0 (0%) 11.5%
During the conversation about the passing/ending therapy ($n = 62$)	35 (56.5%)	16 (25.8%) 82.3%	8 (12.9%)	3 (4.8%) 17.7
During the parting process ($n = 61$)	26 (42.6%)	18 (29.5%) 72.1%	5 (8.2%)	12 (19.7%) 27.9%
During the aftercare ($n = 64$)	36 (56.3%)	11 (17.2%) 73.5%	2 (3.1%)	15 (23.4%) 26.5%

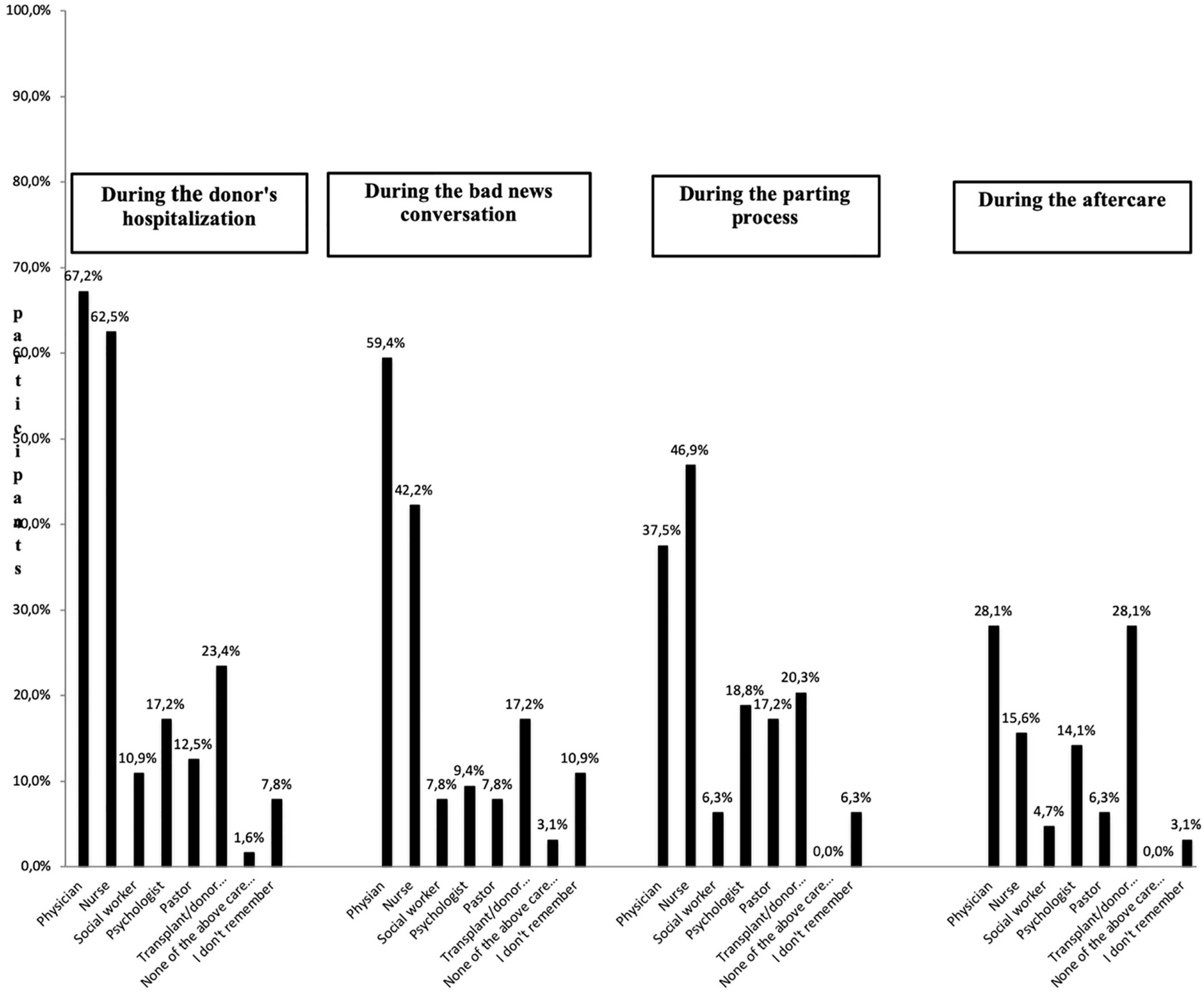

Fig. 2. Percentages of respondents who reported receiving emotional support from the different health care providers during the different phases of the donor process.

those family members who take no initiative or are less communicative. The communication about the death/ending therapy was indicated as tactful for almost all of the participants and most reported they received emotional support. The EDHEP guideline to organise a *separate conversation about the passing and the donation* possibility was not done in the majority of cases [22] . Only when the family has clearly understood the loved one is dead, donation can be mentioned, preferably in a different conversation. A break of at least 15 min is recommended between the two conversations [7,13,14,27,34,35]. This is important just because of the grieving process the families are in. Moreover, after discussing donation another pause is recommended followed by a conversation meant to answer and clarify all questions and doubts the relatives may have [15,27,34,36]. In this study the 15 min rule seemed not always applied by the caregivers, however, it may always be that some families do not experience a pause of 15 min as sufficient to be identified as a separate conversation. We do know that there is a general trend that family members initiate more the conversation about donation during the 'passing/ending therapy conservation' than a few years ago, this may be explained by more awareness campaigns on donation and transplantation by the government. However this is not applicable for our sample from 2009 until 2014 were the majority of the donations the health care provider initiated the conversation.

The giving time to think it over was perceived to be too little for those who regretted their consent. This is in line with the findings of Rodrigue et al. who found that there is a relation between not getting enough time to discuss the donation and having regrets [31]. However, it is not sure that giving a little bit more time could solve this, as we know that in the light of the time needed to accept a loss (as a condition for making rational thinking possible about such emotionally items), the moment of the decision to donate comes always too early [15]. The message of the death of their relatives brings the family in shock, which leads to confusion and dysfunction in perception of information [32,33]. The number of families who felt they had too little time to decide was the same as those who found they had not enough information. This could underline our assumption that rationally capturing the information about donation procedure is difficult at that moment, taking into account the phase of mourning and the emotional state they are in [15]. In our study we found confirmation of this assumption in the comments of the family members who regret their decision to agree with the donation. However we have to note that it is important to take into account the fact that the families who regret donation in this study is a very small group, most (95.3%) of the relatives had no regret of the donation. Nevertheless it can be an important hypothesis to understand why families refuse the donation of their relative. Regarding the applied *communication regarding donation,* the majority indicated that it was tactful, which is according to the international recommendations [26]. In almost the half of the families organ donation had been discussed earlier before the death of the beloved occurred but only a quarter of the relatives knew the deceased wish to donate. It is shown that donation was perceived as less stressful for the relatives when the donor had an expressed will to donate [15]. In some families donation caused discussions and disagreement. These results show that although in recent years a positive trend is seen that relatives have more knowledge about the possibility of donation, it remains important to continue to make efforts on sensitizing and informing the community about donation, and to encourage people to share their views on the topic with family and friends [5,6,37].

Interestingly, the families who initiated the subject of donation themselves had the idea to get little time to say goodbye to the deceased. The others had the idea they have got enough time.

A possible item of improvement is that only half of the relatives reported the caregivers informed them about the possibility to visit again the deceased after the organ procurement. Not all of the families who got the opportunity were positive about it, nevertheless the decision if they need this and can cope with this should be on them. Because half of them was concerned the corpse of their relative would be mutilated, we can assume that some team members are afraid they make the situation emotionally to difficult when they propose this. On the other hand, also 35% reported concerns about not being be able to see their relative after the organ procurement. Most of the participants had the feeling they could count on the team for *emotional support* during the time their relative was on the UCI. During the parting phase the percentage of families who reported emotional support from the team of caregivers drop, this remains the same in the aftercare phase, the recommendations say the healthcare team should give emotional support to the family during the whole donation process [7,23,27,34,38,39]. The relatives felt the physicians play the biggest role in the communication as in the emotional support. Only in the parting process the nurses are perceived as giving more emotional support. In a study of Morton et al. who looked at the impact of the EDHEP workshops on the communication skills of physicians and nurses, they found that the workshop only lead to change in communication skills in physicians, not in nurses [40]. Unfortunately, an evaluation of attendance in the EDHEP workshops in Belgium (Flanders) in the period 2015–2017 taught us that only 9% of the participants were physicians [41]. Despite the fact that many nurses (77%) were interested in following the workshop, the implementation is not evident. In line with earlier findings, it is clear that organizers have to think on solutions to change this balance and reach more physicians. The other participants were transplant and donor coordinators, social workers and psychologists. In our study we see that in the aftercare phase of the donor procedure the part of the specialized health care providers such as the transplant and donor coordinators seem to emerge. This could be linked with the fact that most families wished information about the condition of the acceptors, also in the long run. Although a lot of them would like to receive a letter from the acceptors, less was interested in the self-care group of donor families. So, it is important to realize that these contacts are perceived as something different than getting neutral information and should not be imposed. Psychologists seem to be equal present in the hospitalization and parting phase but are limited involved in the conversations on death and donation. To which extent it is opportune and beneficial to involve psychologists more in the whole donation procedure should certainly be explored: theoretically and practically/financially. A study of Adanir et al. reported relatives who received psychological support from the psychologist had a more positive point of view about organ donation, were given enough time and were encouraged to express their emotions [42]. Further studies must confirm these findings are solely linked at the interventions of psychologists and are not linked to the other disciplines. Finally, we found no relationship between the experienced emotional support and more or less information, nor time given to decide, so shortage of time can't be used as an excuse to be supportive. Al lot of studies have shown that the described advantages for the relatives of a good communication and emotional support during the donor procedure are very beneficial: facilitating a less stressful donation decision making process, satisfaction about the decision and the healthcare, and optimizing the psychological well-being of the families after donation. This study has some limitations. First, this study included only families that agreed to donation. Families that did not agree were not included. This study did not want to improve consent rates, but only aims to evaluate and try to improve the existing procedures concerning communication. A following study will focus upon this group. Second, the response rate of this study was low (32%), but comparable with other self-report studies (between 35% and 40%) [12]. So, we have to be aware that the power of the statistical testing is low. Unfortunately, we have no information about non-participation in the study. It may well be that families with very good or bad experiences responded, whereas families with average experiences didn't bother to respond. Another possible reason is that donor families no longer want to elaborate on what they have experienced, as it remains confronting and emotional, as we learned from responses during the constructing phase of the questionnaire. Third, the retrospective nature of the survey with difference between the time of measurement and donation (period of time varied from 19 to 93 months, with a median of 48 months) may bias the results and experiences of the families. In conclusion, overall the families in our sample experienced the communication and emotional support in the donation process as tactful and satisfying. However, the results also showed that other disciplines such as nurses, psychologists and transplant and donor coordinators could be more intensively involved in the procedure in order to realize a good and continued support during the whole process. The Donor Family questionnaire (DFQ) is a promising tool to enable caregivers to evaluate their approach of the families of donors in the future in a conform manner. We recommend hospitals to do this evaluation on a regular basis

Declaration of Competing Interests

There is no conflict of interest.

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Appendix A. The DFQ

The donor's hospitalization at the intensive care unit

1. My loved one was well taken care of.
    o Totally agree
    o Somewhat agree
    o Somewhat not agree
    o Not at all agree

Comments:…

2. I was informed when there were changes in the medical condition of my loved one.
    o Totally agree
    o Somewhat agree
    o Somewhat not agree
    o Not at all agree

Comments:…

3. How many meetings were organized to talk about the medical condition of your loved one.
    o Enough

(continued on next page)

o Too much
o Very little

Comments…
These meetings were held by who's initiative?

o My family/myself
o The caregivers

4. The information about the condition of my loved one was given in a tactful manner:
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:…

5. My family and I were given emotional support by the caregivers.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:…
From who did you receive emotional support?

o Physician
o Nurse
o Social worker
o Psychologist
o Pastor
o Donor – or transplant coordinator
o Another
o I don't remember

The bad news conversation (passing/brain death/ending therapy)

6. The bad news conversation took place in a separate room.
o Yes
o No

Comments:…
Where did the conversation took place?

o At the ICU
o Somewhere else: ….

7. Who was present during this conversation?
o Which family members? …
o Which caregiver? …

8. The bad news was given in a tactful manner.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:…

9. There was the possibility to ask questions during this conversation.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:…

10. I was given emotional support during this conversation.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:…
From who did you receive emotional support?

o Physician
o Nurse
o Social worker
o Psychologist
o Pastor
o Donor – or transplant coordinator
o Another
o I don't remember

11. The caregivers of the intensive care unit provided enough time for this conversation.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:…

The donation conversation

12. The conversation about organ and tissue donation was tactful.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments: …

13. How much explanation did you receive about the donation process.
o Enough
o Too much
o Very little

Comments: …

14. Did the conversation occur in a separate conversation after the bad news discussion had taken place?
o Yes (if yes, go to question 15)
o No

If no: Who first mentioned donation?

o I/my family brought up the subject
o A caregiver brought up the subject (who? ….. …………………………………………..)

15. How much time was given to think about organ and tissue donation?
o Enough
o Too much
o Very little

Comments: …

16. Where did the donation conversation take place?
o By Telephone
o In emergency room
o In the intensive care unit
o Else where

17. A second conversation was proposed to clarify all doubts and insecurities about donation.
o Yes
o No

Comments: …

18. I felt it was up to me to decide.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments: …

19. I felt free to decide to donate all or certain organs.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments: …

20. Organ donation had been discussed earlier in our family.
o Yes
o No

Comments: …

21. I knew of my loved one's wish to be a donor.
o Yes
o No

Comments:…
If yes: I agreed with that opinion:

o Yes
o No

22. Were there disagreements among family members about donation?
o Yes
o No

Comments:…

23. I was concerned the corps of my beloved would get mutilated?
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:… .

24. I was concerned I wouldn't be able to see the body afterwards?
o Totally agree

o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments: …

The parting process

25. How much time did you get to say goodbye to your loved one.
o Enough
o Too much
o Very little

Comments:.. .

26. How much privacy did you receive to say goodbye.
o Enough
o Too much
o Very little

Comments:…

27. During the parting process I could count on the caregivers for emotional support.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments:… .
From who did you receive emotional support?

o Physician
o Nurse
o Social worker
o Psychologist
o Pastor
o Donor – or transplant coordinator
o Another
o I don't remember

28. It was proposed to me to greet my beloved after the organ donation.
o Yes
o No

Comments: …
How did you experience this?

o Positive ….
o Negative ….

The aftercare

29. After the donation I was aware I was welcome at the hospital for a supportive conversation.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments: …
Who's contact information did you receive? …..
Who did you contacted? …
From who did you receive emotional support?

o Physician
o Nurse
o Social worker
o Psychologist
o Pastor
o Donor – or transplant coordinator
o Another
o I don't remember

30. Were you aware of the possibility to contact the transplant coordinator for more information about organ donation?
o Yes
o No

Comments:…

31. I was interested to receive information about the condition of the receivers of the organs.
o Yes
o No

Comments: …
I also want to be kept informed in the long term.

o Yes
o No

32. I am/was interested to get a letter from the receivers(s) of the organs.
o Yes
o No

Comments: …

33. I wanted to receive information about associations of donor families.
o Yes
o No

Comments: …

34. I regret my loved one donated organs.
o Totally agree
o Somewhat agree
o Somewhat not agree
o Not at all agree

Comments: …

35. The donation influenced my grieving process.
o No
o Yes, in a positive way: …in a negative way: …

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