

Received: 2019.11.26
Accepted: 2020.01.09
Published: 2020.03.17

Optimizing Organ Donation: Expert Opinion from Austria, Germany, Spain and the U.K.

Authors' Contribution:
Study Design A
Data Collection B
Statistical Analysis C
Data Interpretation D
Manuscript Preparation E
Literature Search F
Funds Collection G

ABCDEF 1,2 **Fabian Becker**
B 3 **Keith J. Roberts**
D 4 **Miriam de Nadal**
B 5 **Michael Zink**
B 6 **Philipp Stiegler**
B 7 **Sonja Pemberger**
B 8 **Teresa Pont Castellana**
B 6 **Christian Kellner**
B 9 **Nick Murphy**
B 2 **Alexander Kaltenborn**
BE 2 **Annette Tuffs**
ABDE 1 **Volker Amelung**
ABD 1 **Christian Krauth**
B 10 **Janice Bayliss**
ABCDEF 6 **Harald H. Schrem**

1 Department of Epidemiology, Social Medicine and Health Systems Research, Hannover Medical School, Hannover, Germany
2 Management Team of the Transplant Center, Hannover Medical School, Hannover, Germany
3 Liver Unit, Queen Elizabeth Hospital, University of Birmingham, Birmingham, U.K.
4 Department of Anesthesiology, Surgical Intensive Care Unit, Hospital Universitari Vall d'Hebron, Vall d'Hebron Barcelona Hospital Campus, Barcelona, Spain
5 Department of Anesthesiology and Intensive Care Medicine, General Public Hospital Brothers of Saint John of God, St. Veit/Glan and General Public Hospital of the Order of Saint Elisabeth in Klagenfurt, Head of the Transplantation Advisory Board, Klagenfurt, Austria
6 Department of General, Visceral and Transplant Surgery, Medical University Graz, Graz, Austria
7 Intensive Care Unit 2, KABEG Klinikum Klagenfurt am Wörthersee, Klagenfurt, Austria
8 Transplant Coordinator, Donation and Transplant Procurement and Management, University Hospital Vall d'Hebron, Barcelona, Spain
9 Critical Care and Anaesthetics, Queen Elizabeth Hospital, University Hospitals, Birmingham, U.K.
10 Midlands Organ Donation Services Team, NHS Blood and Transplant and Queen Elizabeth Hospital Birmingham, Birmingham, U.K.

Corresponding Author: Fabian Becker, e-mail: fabianbecker1904@outlook.de
Source of support: Departmental sources

Background: Organ donation-rates using deceased donors and organizational approaches to organ donation differ drastically between countries at a similar level of health care as measured by the Euro Health Consumer Index (EHCI).

Material/Methods: Expert opinions from intensive care nurses, physicians, transplant coordinators and transplant surgeons from Austria, Germany, Spain, and the U.K. were obtained in semi-structured interviews followed by qualitative content analysis. Results were reported back to all interview partners to identify potential controversies and consensus recommendations.

Results: No controversies could be detected. On a variety of beneficial factors an interprofessional consensus between interview partners could be reached: A) The relevance of standardization of the screening for potential donors, the family approach and training; B) standards and best-practice procedures should be regulated and supervised by state authorities; C) full transparency and the prevention of scandals is essential; D) overburdened intensive care unit (ICU) doctors need to be supported by full-time in-house special nurses who organize donor evaluation, transport logistics and pastoral care, if required; E) public awareness campaigns are helpful; F) a broad public consensus on the concept of donation after brain and cardiac death is essential; G) incentives for the reporting of potential organ donors are inappropriate; H) an opt-out system alone is not sufficient.

Conclusions: Expert opinions from different professional backgrounds from different European health care systems reach a broad consensus on the most relevant issues for the improvement of organ donation.

MeSH Keywords: **Delivery of Health Care • Expert Testimony • Qualitative Research • Tissue and Organ Procurement**

Full-text PDF: <https://www.annalsoftransplantation.com/abstract/index/idArt/921727>

 5397  6  —  36



Background

Organ transplantation is a standard treatment for organ failure and yet organ donation and transplantation rates widely differ between countries [1–11]. This rate being highest rates in Spain with 47 organ donations per million people (p.m.p.) in 2017 according to the International Registry in Organ Donation and Transplantation, which is in striking contrast to other countries with highly developed medical organizations. For example, Germany is ranked 39th (9.7 organ donations p.m.p.) worldwide and 24th in the European Union (Table 1) [1–11]. Reasons for this international variation are not well defined.

In this context, it is not surprising that in 2017 the mortality rate of patients on the national waiting list for liver transplantation was highest in Germany and the number of liver transplants per million people was lowest when compared to Austria, the U.K., and Spain [2] (Table 1). Furthermore, 1-year survival after liver transplantation in Germany was approximately 20% lower than in the USA and the U.K. [3].

This article demonstrates the impact of low deceased donor organ donation rates by exemplarily focusing on the consequences for those patients who are on the waiting list for a liver transplant. It should be kept in mind, however, that low deceased donor organ donation rates are likely to also affect those on waiting lists for other organs [12].

Striking differences in organ donation rates and transplantation in the EU raise important questions about organ donation and allocation practices as well as distributive justice and ethics as they have major implications on the chances for survival and quality of life for those, who are in need of organ transplantation.

Organization of organ donation and allocation

Deceased donor organ donation rates and organizational approaches to organ donation differ drastically between countries at a similar level of health care as measured by the Euro Health Consumer Index (EHCI), which uses 48 indicators to determine a score between 333 and 1000 that is intended to represent quality of health care. In 2016 Austria, Germany, Spain, and the U.K. were less than 150 points apart in the EHCI [1].

In the U.K., the NHS Blood and Transplant (NHSBT), a special health authority of the National Health Service (NHS) in the U.K., is responsible for organ donation and donor organ allocation [13] NHSBT employs separate transplant coordinators for donors and recipients and administers the national waiting lists. Organs are allocated according to NHSBT rules which balance urgency and utility, with an emphasis on utility [14].

In Spain, the Organización Nacional de Trasplantes (ONT), a subdivision of the national health ministry, has a similar role when compared to the NHSBT including the definition of organ allocation rules [15]. Since the foundation of ONT in 1989, yearly donation rates have increased from 14 to 47 p.m.p. in 2017 [2].

In contrast to Spain and the U.K., Austria and Germany are members of the Eurotransplant (ET) consortium, which currently has 8 member states. Their national waiting lists are administered by the Eurotransplant Foundation in Leiden, Netherlands, with the mission to enable cross border organ allocation. ET also executes national allocation rules on behalf of its member countries [16].

In Austria, allocation rules are issued by the Transplantation Advisory Board and approved by order of the ministry of health. Apart from kidneys, transplant centers allocate organs, based on medical judgement, to individual patients [16]. In Germany, allocation rules are issued by the Standing Committee Organ Transplantation of the Bundesärztekammer (German Medical Council), a registered society [17].

In Austria, 4 coordination centers, which are located in the regional transplant centers, coordinate the assessment of potential organ donors, transfer donor data to ET and organize organ procurement operations by surgeons from the regional transplant center [16].

In Germany, the assessment of potential organ donors, the transfer of donor data to ET and the organ procurement procedures are organized and executed by the foundation Deutsche Stiftung Organtransplantation (DSO) [18]. Transplant commissaries are in charge of the detection of potential donors in donor hospitals.

Differences in organizational approach between Austria, Germany, Spain, and the U.K. may have a significant impact on organ donation rates. Other factors might be the use of incentives, underlying values, available resources, and cultural and organizational aspects. These issues can be best assessed initially with a qualitative approach followed by quantitative surveys.

The current qualitative study on expert opinions on organ donation originating from different national organ donation systems with strikingly different organ donation rates in Austria, Germany, Spain, and the U.K. aims to highlight areas for systematic improvement of organ donation. This could be particularly beneficial to countries with low organ donation rates. Experts from different countries may reach a broad interprofessional consensus on their insights into relevant factors for the improvement of organ donation.

Table 1. Descriptive statistics on population, organ donation and liver transplantation based on the report by The European Council as well as data on minorities in 4 countries.

	Variables	Austria	Germany	Spain	U.K.	EU
All donor organs affected	Population in millions	8.7	82.1	46.4	66.2	508.9
	Medium age	44	47.1	42.7	40.5	41.7
	Deceased donors per million people (p.m.p.)	24.5	9.7	47.0	22.5	22.3
	Rank in the world-wide national comparison of realized deceased organ donations p.m.p. in 2017	9	39	1	11	n.a.
	Rank in the EU-wide national comparison of realized deceased organ donations p.m.p. in 2017	8	24	1	9	n.a.
	Rank in the national comparison between the 8 Eurotransplant member countries in realized deceased organ donations p.m.p. in 2017	3	8	Not a member of Eurotransplant		n.a.
	ICU/IMCU beds per 100 000 population	21.8	29.2	9.7	6.6	10.1
Only donated livers	DCD/p.m.p. (2016)	0.7	0	10.7	9.3	1.7
	LDLT/p.m.p. (2016)	0.1	0.6	0.6	0.5	n.a.
	Liver transplants per million people	18.5	10.0	26.9	15.3	15.69
	Patients waiting for donor livers (n)	276	2524	1985	1730	16064
	Deaths on the liver waiting list (n)	18	310	60	65	990
	Waiting list Mortality, liver? (%)	6.5	12.3	3.0	3.8	6.2
	Liver donation rate 2016	17.9	11.0	25.1	14.7	11.9
	Rates of pediatric donations (>15 years)	0.9	1.4	1.3	1.5	0.7
Funding		Healthcare insurance companies	Healthcare insurance companies	State	State	n.a.
Minorities	Christian	80.9%	57.2%	67.4%	59.5%	72%
	Muslim	4.2%	5%	3-5%	4%	2%
	Others	5%	9%	1%	3.3%	3%
Education	Low	23.7	14.9	61.9	28.2	34.2
	Medium	54	59.3	16.9	38.4	44.1
	High	22.3	25.8	21.3	33.4	21.7

The number of ICU/IMCU beds per 100 000 population, DCD/p.m.p., the share of the population by educational attainment level and selected age group 55 to 74 years old, 2018 (%), and funding in the respective health care systems [1–11] (n.a.=not applicable).

Table 2. Number and types of participating healthcare providers by country.

Austria	Germany	United Kingdom	Spain
1 Transplant center	1 Transplant center	1 Transplant center	1 Transplant center
2 Regional Public Hospitals	1 Transplant coordination office	1 Transplant coordination office	

Material and Methods

Recruitment of interview partners

Semi-structured interviews were conducted with 1 intensive care physician and 1 intensive care nurse experienced in the care of potential organ donors as well as 1 organ retrieval surgeon and at least 1 transplant coordinator in each of the countries Austria, Germany, Spain, and the U.K. (for more details on participating health care providers see Table 2). The interview partners were recommended by transplant experts from Graz (Austria), Hannover (Germany), Barcelona (Spain), and Birmingham (U.K.). The interview partners had to work at a transplant center and had to fulfill certain criteria which were asked in the questionnaire (see also in the appendix of the revised manuscript). We have approached 21 potential interview partners. Four potential interview partners declined to participate in the study. A total of 17 interview partners were interviewed (4 in Austria, Spain, and Germany and 5 in the U.K. – with 1 donor transplant coordination and 1 recipient transplant coordinator in the U.K.).

The interviews were conducted by the research team (co-authors FB and HS) in the respective professional setting; their duration ranged from 10 to 30 minutes.

Interview guide

The initial research team (co-authors FB, VA, and HS) developed a pre-defined interview guide and questions based on information gathered from literature on organ donation systems and organ donation rates in Austria, Germany, Spain, and the U.K. as outlined in the introduction section of this paper. The interviews were conducted in Austria and in Germany by a native speaker. The interviews in the U.K. and Spain were conducted in the English language with interviewers having an English language capability competence at least at level C1. The interview guide aimed at obtaining information-rich content concerning the experts' personal experiences and opinions including their impressions of interrelations with their social professional environment. Interview questions were handed out to the interview partners prior to the interviews. They are shown in the Supplementary Material.

Ethical considerations

All interview partners signed an informed consent to participate in recorded interviews and to the anonymous use of the obtained data for the purpose of this study. The pre-defined leaflet for the declaration of informed consent (see also in the appendix of the revised manuscript) of all interview partners and all interview questions were fully approved by the ethical committee of Hannover Medical School on April 6, 2017 (reference number 3501-2017).

Qualitative data extraction and categorization

Interviews were transcribed and translated into English by the initial research team (co-authors FB, VA, and HS), if necessary. The interviews assigned the interviewer's professional role and country of professional activity. The transcribed interview data were analyzed qualitatively using the method for qualitative content analysis as previously described [19-24]. Based on this approach, all interview transcripts were carefully screened for information that was deemed relevant. The data extraction rule list was derived from the interview content and its value for the scientific aims of this study (Table 3). Extracted information was subjected to a stepwise induction of codes that were separated into different categories and subcategories in close dependence of the originally obtained interview material (Table 4). The coding was done by co-authors HS and FB from the initial research team. Any differences were discussed in colloquia and resulted in a final consensus for the coding. The qualitative data analysis software MAX QDA (Version 12.3.3 (2017-11-30) was used for this procedure.

Quality assurance, validity check of obtained results and consensus process

All interviews were initially summarized to highlight the key statements of experts regarding certain issues and questions. This summarization process was conducted as an initial quality assurance process and evaluated by the initial research team with the goal of assessing plausibility prior to final qualitative analysis (data not shown).

The results of the final analysis, as summarized in the manuscript of this article, were sent to all interview partners with the goal of obtaining their approval for the plausibility and

Table 3. List of content extraction rules applied.

1. Information from answers are extracted into the category on which the information has the highest informative value
2. In case information from an answer does fit into more than one category, the assignment is discussed with colleagues. The aim remains to find the category on which the information has the highest informative value
3. Filler words will not be extracted, and grammatical mistakes will be, by avoiding deviation with regard to content, corrected
4. During transcription necessary translation will be done

Table 4. Category list with defining explanations.

Categories	Subcategories	Definitions
Donation process	Donor evaluation	Qualitative information about the donor evaluation process
	Work of Transplantation coordinator	Qualitative information about the work of the transplantation coordinator
Donation numbers	Donation rate	Quantitative information about donation rates
	Rate of brain death diagnostic	Quantitative information about brain death diagnostic rates
Health care system	Incentives for doctors	Information about possible incentives for doctors
	Transplantation scandals	Information about the existence and effects of national transplantation scandals
	Relationships and cooperation between transplantation centers and donor hospitals	Information about possible relationships and cooperation between the named institutions
	Allocation	Information about the allocation of the donor organ liver
	People's opinion	Information about the public opinion of the people about donation and/or transplantation processes and/or the general transplantation system and/or medicine
	Framework for donation	Factors that have a comprehensible possible effect on organ donation in every sense and are not fitting in another category
	Regulations	Information about formal regulations, protocols and laws
	Number of transplantation centers	Information about possible effects of the number of transplantation centers
	Advertisement	Information about advertisement for organ donation and possible effects
	Family	Family decision
Family approach		Information about the approach on families to request a decision on organ donation by a deceased relative
Rate of family approaches		Information about the rate of family approaches

correctness of the analytical results and in order to exclude potential misunderstandings or false interpretations. Since only a part of the answers could be quoted, and since bilingualism can always lead to translation errors and misunderstandings, we wanted to ensure that the experts' approach and their opinions were correctly represented in the final manuscript. The interview partners were asked to provide feedback

on the final manuscript and to provide their input to the discussion and the conclusions of the manuscript with the goal to reach a consensus of interviewed experts. Interview partners who provided a profound feedback and/or input were asked to become co-authors of the manuscript. Additionally, this process was also used to achieve an interprofessional consensus on the main recommendations for the improvement

of organ donation systems and to detect potential controversies. Another goal of this approach was to obtain the input of all interview partners for the interpretation and discussion of obtained results.

Some of the interview partners who provided additional input on improving the manuscript have accepted the initial offer to become a co-author although this would practically nullify their anonymity.

Results

Results of qualitative content analysis

Each of the following paragraphs summarizes 1 of the categories (Table 4) of the extracted content obtained in the expert interviews.

Donor evaluation

A major point, which was stressed by most experts in Spain, the U.K., and Austria, was the outstanding importance of the role and the work of the transplant coordinators, especially in the U.K. and in Spain, where special donor nurses or transplant coordinators organize donor evaluation and transport logistics, and coordination with procurement surgery teams, mostly as a full-time job. This support relieves intensive care physicians from the work burden associated with donor evaluation, transport logistics, and coordination.

In Germany, donor evaluation is almost exclusively organized and coordinated by intensive care doctors while transplant coordinators of the DSO are rarely asked for support. In recent years, evaluating potential organ donors is seen as an increasing burden by intensive care doctors from all 4 countries and all German experts. Older, multi-morbid potential donors may contribute to this perception.

“...clinical personnel on ICUs are overloaded with work and this is combined with a shortage of qualified personnel. This doesn't make it a natural decision to (report a potential organ donor), if potential organ donors are detected...” [Germany/Transplant Coordinator/paragraph 96].

“And without a professional consultant, who takes responsibility, who helps doctors and has experience, hospitals often won't participate.” [Germany/Organ Retrieval Surgeon/paragraph 66].

In Spain and the U.K., the demanding work of donor evaluation is nearly entirely organized and coordinated by full-time transplant coordinators (Spain) and full-time special donor nurses (Special Nurse Organ Donation or SNOD) (U.K.), who

concentrate on this task. In addition, they are an integral part of the family approach and help to prepare it.

In Austria, defined local coordination centers, which are located in transplant centers, report potential organ donors from their region to the regional transplant center. Transplant coordinators belong to the transplant center and advice and support smaller hospitals. Since 2017, the coordination center obtains a second opinion from another transplant center prior to refusing an organ.

“...the doctors on ICU are getting help from the special nurses, which makes it easier for them and really let them focus on medical issues of the patient and not so much on bureaucracy.” [U.K./Intensive Care Nurse/paragraph 237].

In Germany, not all hospitals have standard screening procedures for potential donors. Therefore, organ donation depends on the initiative of individuals who are working extra time.

“You can ask anybody in Germany. Organ donation heavily depends on the commitment of individuals in hospitals. We see a clear change in donation rate when someone, who encouraged his or her colleagues and kept organ donation running in the hospital, leaves the hospital.” [Germany/DSO Transplant Coordinator/paragraphs 103, 104].

Intensive care physicians from all 4 countries emphasized that intensive care bed capacity was a potential barrier to donation particularly when they were at or close to capacity. The needs of the living patients within their organization were considered over the needs of deceased organ donation from deceased patients.

The median age of patients on the waiting lists were similar between the 4 countries (see Table 1), which is why our experts saw no reason for the different donor rates due to patient age.

Incentives to report a potential donor

In Austria, Spain, and the U.K., there are no financial incentives to report potential donors. In Austria, the ICU doctor said that measures are taken if doctors are not fulfilling their obligation to report potential organ donors. These measures would consist of consultations between the transplantation commissioner and the respective physician.

“The culture has also changed so that organ donation and transplantation is more part of normal work, therefore incentives don't make so much sense anymore.” [U.K./Special Donor Nurse/paragraph 173].

Table 5. Summarized answers to questions: Who should be part of team that approaches families to ask for approval of organ donation of their deceased relative, and who should lead this approach?

Interview partners	Possible participants	Germany		United Kingdom				Spain				Austria						
		Should participate		Should lead approach		Should participate		Should lead approach		Should participate		Should lead approach		Should participate		Should lead approach		
		Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	
ICU Doctor	Doctor	X		X		X		X		X		X		X		X		
	Nurse	X			X	X			X	X			X	X			X	
	Surgeon	X			X		X			X		X			X		X	
	Tx-coordinator	X			X	X			X		X			X			X	
Nurse	Doctor	X		X		X		X		X		X		X		X		
	Nurse	X		X		X		X		X		X		X			X	
	Surgeon	X		X			X		X		X			X		X		
	Tx-coordinator	X		X		X		X		X		X			X		X	
Retrieval surgeon	Doctor	X		X		X		X		X		X		X		X		
	Nurse	X		X		X		X		X		X		X			X	
	Surgeon		X	X		X		X		X		X		X		X		
	Tx-coordinator	X		X		X		X		X		X			X		X	
Tx-coordinator	Doctor	X		X		X		X		X		X		X		X		
	Nurse	X		X		X		X		X		X		X		X		
	Surgeon		X	X		X		X		X		X		X		X		
	Tx-coordinator	X		X		X		X		X		X			X		X	
Recipient nurse	Doctor	/				X		X		/				/				
	Nurse					X		X										
	Surgeon						X		X									
	Tx-coordinator					X		X										

Tx – transplant, ICU – Intensive Care Unit.

The German intensive care physician agreed, stating as justification that the impression could be created that someone could influence the process with cash or other means.

“...first there are talks, when potential donors are not reported, later interventions from higher positions.” [Austria/Organ Retrieval Surgeon/paragraph 510].

Family approach

In Spain, the position of the transplant coordinator has been established for many years and processes are standardized. This includes the basic family approach which focuses on the last will of the potential organ donor concerning organ donation.

Families are approached by the ICU doctor in charge of the patient, who always involves a transplant coordinator prior to the family approach. He also informs the family about the death of their relative. Nurses and pastoral care givers can be involved, if requested by the family or considered as necessary or helpful by the transplant coordinator.

In the U.K. and Germany, there are no standard procedures for the family approach. In the U.K. it is usually a joint approach by the consultant and the special nurse. Usually, the ICU consultant brings up the possibility of donation and the special nurse takes it from there. In Germany, the DSO transplant coordinator is rarely invited to join the initial family approach, which is mostly conducted by the treating doctor on the ICU.

In Austria, the family approach is considered the task of the ICU doctor and the ICU nurse only. An involvement of transplant coordinators is considered inappropriate, partly because they usually are medical students without professional training and standing. Nearly all experts also agree that surgeons should not be involved in the family approach (for details see Table 5). In an open question on the justification, it was stated that because of their perceived conflict of interest, surgeons should not be involved in the family approach. Families should ideally be approached by members of hospital staff who are already known and trusted.

As an addition to the topic of family approaches, the British surgeon explained that an opt out system would help with these approaches and would significantly reduce bureaucracy. The ICU doctor from the U.K. is also looking forward to the results of the introduction of an opt-out system in Wales. An opt-out system, according to most of our experts, would encourage discussion within families, but it remains questionable whether an opt-out system would result in an increase in organ donation rates.

Family decision

In Germany and the U.K., families often do not know the last will of their relative concerning deceased donor organ donation. This situation fosters the tendency of disapproval for organ donation. People avoid talking about death and organ donation and do not know their relatives' opinion. This experience was shared by all experts from all countries apart from the Spanish surgeon.

"...and in some cases, they don't know if an approval would be in line with the patient's will and to be on the safe side they deny" [Germany/ICU Doctor/paragraph 11].

In Spain on the other hand, a surgeon told us:

"...families talk a lot about donation, it is not something that people are afraid to talk about." [Spain/Organ Retrieval Surgeon/paragraph 397].

One aspect repeatedly mentioned by the experts was that of religion, which is why we have also presented data on percentages of religious groups and minorities in the individual countries in Table 1.

"But I heard that Muslims frequently denying deceased donation, and this will play an increasing role in this country." [Germany/DSO Transplant Coordinator/paragraph 110]

"And Muslims refuse also more often." [United Kingdom/Special Nurse Organ Recipient/paragraph 221].

"I have a theory that families in catholic countries are not ashamed as much to talk about death." [Spain/Surgeon/paragraph 397].

Public opinion and transplant scandals

In Spain, the transplant system enjoys a deep trust by the public:

"People are very proud of the Spanish model and know about the advantages or better the benefit of transplantation." [Spain/ICU Doctor/paragraph 311].

This is in contrast to Germany where mistrust in the transplantation system due to past scandals is prevalent, accompanied by uncertainty concerning transplantation because of ignorance.

"Additionally, compared to other countries, especially other Eurotransplant countries, opinions about transplantation medicine deteriorated after a series of manipulations of waiting list data in 2012 in some transplantation centers..." [Germany/DSO Transplant Coordinator/paragraph 95].

"The people are afraid of things they generally don't know in detail." [Germany/Intensive Care Nurse/paragraph 36].

"Interestingly, when there are bad media reports on that topic in Germany, we also have a rise in denial rates." [Austria/ICU Doctor/paragraph 424].

Relationship and cooperation between transplant centers and donor hospitals

In Austria, there are regular meetings between all centers and hospitals where the current status of cooperation is evaluated and optimized. The relationships between transplant centers and hospitals are generally stable.

In Germany, Spain, and the U.K., these co-operations only exist via the procurement teams of the transplant centers that perform the organ procurement surgery in donor hospitals. Procurement teams are organized and coordinated by the DSO in Germany, the NHSBT in the U.K., and the ONT in Spain.

"The retrieval teams are ambassadors and they have an important impact on the relationships. Especially when the surgery is difficult, you need the spirit of feeling as one team. Debriefing with all participants helps to get that spirit." [U.K./Special Donor Nurse/paragraph 194].

In the U.K. and Germany, a letter about the results of the donation and transplantation is sent to everyone involved in organ donation. Reportedly, this is very helpful and increases motivation.

Table 6. Summarized expert recommendations for a systematic improvement of organ donation systems.

Categories	Expert recommendations
Donor evaluation	Standardization of screening for potential donors on intensive care units
	Employment of full-time in-house transplant coordinators in large hospitals with neurosurgical departments
	In-house transplant coordinators organize donor evaluation, transport logistics and coordination of procurement surgery teams
Incentives	Incentives for doctors or nurses to report a potential donor are not required
	Failure to report potential organ donors must have consequences in the form of a confrontation by clinical superiors
Family approach	Standardization of the family approach and training for intensive care unit doctors and nurses and in-house transplant coordinators
	Additional involvement of pastoral care and representatives of religions whenever requested
Family decision	Awareness campaigns should encourage families to discuss organ donation
	An opt-out system for organ donation will more likely encourage families to discuss organ donation as compared to an opt-in system
Public opinion	Public trust must be earned by the transplant community by providing full transparency in organ donation and transplantation and by the effective prevention of scandals
	A broad consensus in society in favor of organ donation and transplantation as well as the concept of brain death and/or the concept of donation after cardiac death is required
Cooperation between hospitals	Transplant centers and regional donor hospitals should be able to cultivate their relations with the goal to improve organ donor evaluation and detection as well as organ donation processes.
	Regulatory authorities should supervise allocation and if necessary, donation and procurement activities, define standards, identify best-practice procedures and make national and international benchmarking mandatory for transplant centers
General	Availability of sufficient resources and structures to ensure 24 hours, 7 days a week support by competent in-house transplant coordinators and pastoral/religious support is helpful

“Two weeks after transplantation, the special donor nurse writes to every member of the team who was involved in the donation and transplantation process.” [U.K./Special Donor Nurse/paragraph 195].

“A direct contact between transplant centers and donor hospitals is realized only via DSO which is writing a feedback letter after transplantation to the donor hospitals informing about what happened with the donated organs.” [Germany/DSO Transplant Coordinator/paragraph 127].

Achieved Interprofessional consensus between experts and potential controversies

Table 6 shows the summarized expert recommendations for a systematic improvement of organ donation systems. Based on these results, all interviewed experts could reach a consensus on the following beneficial factors for improved organ donation rates without any detected controversy:

- The standardization of the screening for potential donors, the family approach and the training are beneficial.
- Standards and best-practice procedures need to be regulated and supervised by state authorities.
- Full transparency in organ donation and the prevention of scandals is essential.
- Overburdened ICU doctors need to be supported by full-time in-house special nurses for organ donation who organize donor evaluation, transport logistics and pastoral care, if required.
- Public awareness campaigns are helpful.
- A broad public consensus on the concept of donation after brain and cardiac death is essential.
- Incentives for the reporting of potential organ donors are ineffective and inappropriate.
- The introduction of an opt-out system alone is an insufficient measure for the improvement of organ donation rates.

The competent authorities, such as the national Ministry of Health and the organizations responsible for organ donation

and allocation, as well as legislative institutions including parliaments and members of parliament will be provided with copies of this article by the authors. In addition, the exchange between experts at congresses and similar meetings should be encouraged, as has already been done by the authors.

Discussion

This study was inspired by a comparison between different organ donation and transplant systems in 4 European countries with the aim of optimizing strategies for organ donation and transplant programs (Table 6). A variety of factors are important – infrastructural, organizational, cultural and political – varying between countries with similar levels of health care and medical standards (Table 1). As this study shows the successful identification of potential organ donors is obviously influenced by the availability of required resources and infrastructures, whereas incentives do not seem to have positive effects. Only Austrian experts stated that on the other hand they impose penalties in the form of a confrontation of the doctor by their superiors.

All experts agreed that the efficient organization of organ procurement, a broad consensus in society on the concept of brain death and/or the concept of donation after cardiac death as well as a positive attitude in favor of organ donation and transplantation are necessary prerequisites for successful organ donation and transplant programs. Deficits in these respects cost patients' lives waiting for an organ transplant. In Germany, according to the DSO, approximately 3 patients die on the waiting list for transplantation every day [25].

“Our interviews as well as the literature suggest that in Germany deficits in the organization of organ donation form the background for low organ donation rates. Deceased donor organ donations declined by more than 30% since 2010 [20]. However, surveys conducted by the Federal Center for Health Education (Bundeszentrale für gesundheitliche Aufklärung, BZgA) found a stable approval rate for organ donation in the public of around 80% since 2012 [26]. A link to the level of education is certainly difficult to make in the meantime. We have included data on educational attainment in Table 1, but were unable to make a correlation with donor rates. The experts' assumptions about links between these 2 aspects were not clear.

Donor evaluation and required resources

All experts from Germany reported in this study an overburdening of the ICU doctors, a shortage of qualified personnel and a lack of experienced consultants who take responsibility and help doctors to identify and evaluate potential organ donors. This may at least partly explain the decline in organ

donation which has been attributed to deficiencies in the recognition and reporting of potential organ donors [27].

Experience from the U.K. showed that hospitals benefit from having lead consultants for organ donation, usually ICU consultants supported by a regional consultant who reviews donation rates in the region's hospitals.

In Spain, standardization of screening for potential donors on ICUs to support clinical decision making increased the realized donation rate [28]. Experts from the U.K. and Spain emphasized the relevance of full-time special donor nurses or in-house transplant coordinators, who organize donor evaluation, transport logistics and the coordination with procurement surgery teams after being identified by the ICU doctor to relieve ICU physicians and nurses from these tasks.

A study from Poland reported that in regions with low donor rates, physicians were more reluctant to start diagnostic procedures to verify suspected brain death when compared to regions with high donation rates. This was mainly due to lack of experience (41.4%) and the fear of family accusations and lawsuits (40.0%) [29].

This study indicates that professional support and training for ICU doctors in respect to organ donation and brain death diagnosis is of high relevance for the development of an efficient organ donation system. Organ donation and transplantation should become part of normal work, as reported by a dedicated donor nurse from the U.K. in this study. It is interesting to note that none of the interview partners was of the opinion that incentives for the reporting of potential organ donors would be appropriate or helpful. This notion is most likely based on the assumption that incentives are generally not required for ducks, who naturally take to the water.

Failures of ICU doctors to report potential organ donors should be detected, quantified, and confronted by clinical superiors and systematically reviewed in peer-review audits. This may help to improve organ donation while individual incentives to report potential organ donors may harm the required public trust in transplantation.

Peer review audits and benchmarking may help to raise awareness of potential organ donors on ICUs. Peer pressure is one of the strongest motivating factors for change of practice. Thus, national programs that emphasize the importance of organ donation and the role of those who identify and manage potential donors is a potential key step in improving donation rates. When there is a collective view across healthcare professionals that donation is an essential component of medical care, then individuals will be much more likely to facilitate donation.

It is interesting to note that all intensive care physicians mentioned the challenge of providing sufficient ICU beds for organ donors. However, Table 1 clearly shows that the U.K. and Spain have significantly fewer ICU beds than Germany and Austria. Nevertheless, the first 2 nations have a higher donor rate in relation to Germany. The problem of too few beds in Germany seems paradoxical.

Family approaches and consent to organ donation

Interestingly, the interviewed experts did not agree on whether the transplant coordinator or the ICU doctor should lead the family approach. However, most experts agreed that the family approach should ideally be undertaken by members of staff already known to the family, typically the intensive care nurses and doctors who treated the deceased potential organ donor. The relationship to relatives improves with the involvement of nurses [30]. This experience is shared by many of the interviewed experts. All experts agreed that the surgeons should be excluded from the family approach to avoid conflicts of interest.

Additional involvement of nurses and pastoral care of the respective religions, if requested by the family or considered as necessary or helpful by the transplant coordinator or the ICU doctor, can be helpful and should be available in all hospitals.

Fixed rules and systematic training for the family approach are likely very beneficial. This notion is in line with previously published studies showing that the type of professionals and structures involved in the family approach do have an effect on the family's consent to deceased donor organ donation [31,32]. This requires additional staff on a 24-hour basis. In the U.K., the presence of a SNOD at time of approach is considered a quality metric and reported back to hospitals if they are not there. The experts pointed out in the interviews that previous discussions about organ donation in families are helpful in order to ascertain the last will of their deceased relative. Awareness and media campaigns should encourage family discussions and should increase public knowledge of transplant procedures, transplant results and transplantation in general. This view is supported by a study from the United States which demonstrated that in African-American families the media strongly influence an individual's willingness to participate in the organ donation process and their commitment to further discuss their decisions with close family members [33]. Feeley and Moon published in 2009 a meta-analysis of 23 different awareness campaigns and found that media campaigns can contribute to a 4% increase in organ donation while interpersonal campaigns account for a 7% increase [34]. However, using both channels together resulted in a 9% increase in donations [29]. However, a handbook on theoretical and practical aspects of communicating about

organ donation and transplantation, which was one deliverable of the EU-Project FOEDUS, came to the conclusion that awareness campaigns have only a small effect on increasing organ donation [35].

Interestingly, none of the experts believed that the explicit consent system (opt-in) versus a presumed consent system (opt-out) for consent to post-mortem organ donation has a dominant influence on the rate of realized organ donations per million inhabitants alone while it may increase awareness of the issue.

Transplant centers and regional donor hospitals should cultivate their relations with the goal to improve organ donor detection and evaluation as well as the whole organ donation process. Such activities should be monitored by a nation-wide organization that functions as a regulatory authority that supervises mandatory peer-review auditions which may recommend mediation for the optimization of organ donation and the required collaboration efforts between institutions and different departments within hospitals.

Regulatory authorities should also supervise organ allocation activities, define standards, identify best practice procedures and make national and international benchmarking mandatory for transplant centers including their relations to donor hospitals. In the United States, all transplant centers are required to have a formal organ procurement organization (OPO) affiliation while United Network of Organ Sharing (UNOS) and Center for Medicare/Medicaid Services (CMS) provide benchmarking for outcomes at donation, utilization and survival [36]. It is interesting to note in this context that comparable regulatory supervision of organ donation is missing completely in Germany, which may contribute to the very low organ donation rates.

We did not ask any direct questions regarding the financing of the respective health systems. In general, the issue of sufficient financing is also a recurring theme in organ donation. However, cuts in the U.K. and Spain in health care systems, as shown in the article "The financial crisis and health care systems in Europe" [19], do not seem to have had any effect on the donor rate.

Consensus on recommendations for the improvement of organ donation

The 17 interviewed experts from different countries and health care systems with large differences in realized organ donation rates provided this study with insights from different professional perspectives based on very different personal experiences. This informed the summarized expert recommendations for a systematic improvement of organ donation systems (Table 6). It is noteworthy in this context that all interviewed

experts easily agreed on an interprofessional consensus on recommendations for the improvement of organ donation systems as described in the results section of this paper.

It should be noted that although these are the opinions of highly professional experts, they do not constitute a formally developed set of recommendations after a formal guideline development process. Furthermore, controversies between experts from different professions and/or different healthcare systems could not be detected. This underlines the homogeneity of the evaluated expert opinions formed under vastly different conditions in regard to organ donation in similarly developed European countries.

The results of this study are of high practical value for the debate on how to improve a national organ donation system. The consensus recommendations defined in this study appear as highly relevant for countries with low donation rates that strive to find a framework for targeted improvements of their organ donation systems.

We believe that this study should encourage a broader international benchmarking initiative that aims at the regular comparison of different national organ donation systems and their targeted improvement. Quantitative follow-up studies on the effects of changes in those areas that were identified

as relevant for organ donation rates in this study should be undertaken to monitor the effectiveness of specific improvement initiatives. Further insights can be expected from such an approach for the future development and optimization of organ donation systems.

Limitations

The differing national legal and regulatory frameworks for organ donation, the number and size of hospitals in a healthcare system, the availability of organ donation after cardiac death (which is prohibited for example in Germany) and the financial reimbursement of the infrastructure for organ donation systems likely also influence the rate of realized organ donations to a relevant degree. These aspects of organ donation were not investigated in this study. The methodology applied in this study can only reach the evidence level of expert opinion.

Conclusions

Expert opinions from different professional backgrounds from different European healthcare systems can reach a broad consensus on the most relevant issues for the improvement of organ donation without controversies with high practical value.

Supplementary Material

Predefined Interview Questions

In 2014, 11.4 people per million inhabitants in Germany donated their liver (Domínguez-Gil and Matesanz, 2015). In the same year, the rate for liver donation in the U.K. was 14.8, in Spain 22.7, and in Austria 16.7 (Domínguez-Gil and Matesanz, 2015).

- How would you explain the rate of liver donation and organ donation in general in your country?
- What are possible incentives for a doctor to report a donor?
- How much time and effort does it take to report a potential organ donor?

In 2013, 12% of the families in Spain denied organ donation from their deceased family member who could have potentially been an organ donor (De la Rosa and Ramón, 2014).

In Spain, the family approach must be done by a team in which several people must be present (Matesanz, 2011).

- What influence does the composition of the consulting team have in the family approach on the decision whether or not to approve an organ donation?
- In your opinion, what influence does the doctor, who is responsible for the potential organ donor, have? Shall he/she approach the family?
- In your opinion, what influence does the nurse, who is responsible for the potential organ donor, have? Shall he/she approach the family?
- In your opinion, what influence does the organ retrieval surgeon, who is responsible for the potential organ donor, have? Shall he/she approach the family?
- In your opinion, what influence does the coordinator for transplantation who is responsible for the potential organ donor have? Shall he/she approach the family?

In 2013, 12% of the families in Spain denied organ donation from their deceased family member who could have potentially been an organ donor (De la Rosa and Ramón, 2014). In Germany 29% of the approached families denied organ donation and in the U.K. 40% of the approached families said “no” to organ donation (DSO, 2015 b, Hopkinson, 2015).

- What possible explanation can you give for the family refusal rate in your country?
- How would you explain the differences between the refusal rates in these three countries?

Liver transplantations are only operated in transplantation centers, but the liver is often donated in other hospitals which are not transplantation centers.

- How do you think the relationships or cooperation is between the transplantation centers and the hospitals around them in this field?

Questions only asked in Germany and in Spain and Austria:

In 2012 and 2013, 22% of patients in the U.K. who were suspected to have suffered brain death at an intensive care unit or in Accident and Emergency department, received no neurological diagnostic for brain death (Hopkinson, 2015).

- Of those patients who were suspected to have suffered brain death in your country, how many do you think were not tested for brain death?

In the U.K. 32% of the families of potential organ donors were not approached (Hopkinson, 2015).

- What percentage of families of potential organ donors was not approached in your country?

Question only asked in Austria:

Doctors in Austria don't have to necessarily follow a denial from the families concerning organ donation if the deceased organ donor approved organ donation while he/she was alive (ÖBIG, 2016).

- Have you been in such situations and what was the family's reaction?

Declaration of Informed Consent

The interview serves to answer the question: “What are the factors for a successful transplantation system with an effective approach to the post-mortem organ donation process after organ donation”?

Experts in different positional backgrounds and with different professions from Spain, the U.K. and Germany are interviewed. The results will be analyzed, compared and published.

Important points of this comparison are the organization, the structure and the attitudes of people who are involved in the organ donation process.

For the analysis we will use highly relevant opinions and experiences, attitudes and assessments.

Our interview partner will stay completely anonymous. All notes and recordings will be completely destroyed after analysis.

The questions give no clue about the answering person. The interview partners are kindly asked to reveal if they are working in a hospital which is a transplantation center or in a donor hospital where organs are not transplanted but organ procurement take place. The interview partners shall reveal in which country they are working, their function, their specialization, their rank at work and if they have taken part at an organ procurement operation, organ transplantation and/or a family approach for consent to organ donation.

Apart from these aspects the recordings of the interview will not contain any personal names or hints to the employer.

I hereby with declare that I participate in the interview fully informed and on basis of my free will based on the conditions described above.

City, date

Name in block letters

Signature

The interviewer declares as the investigator to guarantee and ensure all of the conditions described above.

City, date

Name in block letters

Signature

The Questionnaire

Data of the interview partner:

Country _____

Working place:

Transplantation center Donor-Hospital

Function:

Doctor Coordinator at the transplantation center Nurse

Rank at work

Specialization:

Surgeon for transplantation

Intensive care specialist

Nurse in ICU

Nurse in normal station

Was involved in at least one procurement operation yes no

Was involved in at least one transplantation of an organ yes no

Was present in at least one family approach where the family of the deceased potential organ donor approved organ extraction.
yes no

Was present in at least one family approach where the family of the deceased potential organ donor did not approve organ extraction.
yes no

Criteria for potential interview partners

For surgeons: Must have been involved in at least one procurement surgery and in at least one transplant surgery.

For intensivists (ICU doctors): Must have been involved in at least one family approach where the family of the deceased potential organ donor approved organ donation and in at least one family approach where the family of the deceased potential organ donor did not approve organ donation.

For transplantation coordinators: Must have been involved in at least one family approach where the family of the deceased potential organ donor approved organ donation and in at least one family approach where the family of the deceased potential organ donor did not approve organ donation.

For ICU nurses: Must have been involved in at least one family approach where the family of the deceased potential organ donor approved organ donation and in at least one family approach where the family of the deceased potential organ donor did not approve organ donation. Furthermore, ICU nurses must have had experience in the treatment of potential organ donors on ICU stations.

References:

1. Björnberg A: The Euro Health Consumer Index (EHCI) 2016 Report. Health Consumer Powerhouse, 2017-01-30
2. Domínguez-Gil, Matesanz. International figures on donation and transplantation. Rafael Matesanz, Ed, Council of Europe Newsletter Transplant, 2017; 22 <http://www.transplant-observatory.org/download/newsletter-2017/>
3. World Factbook – Austria. <https://www.cia.gov/library/publications/resources/the-world-factbook/geos/au.html>
4. Rhodes A, Ferdinande P, Flaatten H et al: The variability of critical care bed numbers in Europe. *Intensive Care Med*, 2012; 38(10): 1647–53
5. Worldatlas – Spain religion. <https://www.worldatlas.com/articles/religion-in-spain.html>
6. World Factbook – European Union. <https://www.cia.gov/library/publications/resources/the-world-factbook/geos/ee.html>
7. World Factbook – United Kingdom. <https://www.cia.gov/library/publications/resources/the-world-factbook/geos/uk.html>
8. World Factbook – Germany. <https://www.cia.gov/library/publications/resources/the-world-factbook/geos/gm.html>
9. Giovanella L, Stegmüller K: The financial crisis and health care systems in Europe: Universal care under threat? *Trends in health sector reforms in Germany, the United Kingdom, and Spain. Cad Saude Publica*, 2014; 30(11): 2263–81
10. Educational attainment statistics Eurostat. 2018. https://ec.europa.eu/eurostat/statistics-explained/index.php/Educational_attainment_statistics#Level_of_educational_attainment_by_age
11. World population review. <http://worldpopulationreview.com/countries/median-age/>
12. Saidi R, Hejazii Kenari S: Challenges of organ shortage for transplantation: Solutions and opportunities. *Int J Organ Transplant Med*, 2014; 5(3): 87–96
13. Harvey F, Hamlyn L: Framework agreement between the department of health and NHS blood and transplant 2014. NHS. <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/10894/nhsbt-and-doh-framework-agreement-2014.pdf>
14. Neuberger J: Rationing life-saving resources – how should allocation policies be assessed in solid organ transplantation. *Transpl Int*, 2012; 25(1): 3–6
15. Matesanz R: El Modelo Español de Coordinación y Trasplantes. 2018. <http://www.ont.es/publicaciones/documentos/modeloespanol.pdf> [in Spanish]
16. ÖBIG. Verfahrensweisungen Regeln für die Zuteilung von Organen. 2016. https://transplant.goeg.at/sites/transplant.goeg.at/files/2017-06/VA_Allokation_Vers1_Mai16_Website.pdf [in German]
17. Nashan B, Hugo C, Strassburg CP et al: Transplantation in Germany. *Transplantation*, 2017; 101(2): 213–18
18. DSO (2018). Verfahrensweisungen der DSO gemäß §11 des Transplantationsgesetzes. https://www.dso.de/uploads/tx_dsodl/Verfahrensweisungen_Maerz_2018_GES.pdf [in German]
19. Mayring P: Qualitative content analysis. *Forum Qualitative Sozialforschung/forum: Qualitative Social Research*, 2000; 1(2): 1
20. Mayring P: Qualitative Inhaltsanalyse: Grundlagen und Techniken. 11th ed. Beltz: Weinheim; 2010 (Beltz Pädagogik) [in German]
21. Gläser J, Laudel G: Experteninterviews und qualitative Inhaltsanalyse. Als Instrument rekonstruierender Untersuchungen. 4. Aufl. Verlag für Sozialwissenschaften, Wiesbaden; 2010 [in German]
22. Schildberger B, Zenzmaier C, König-Bachmann M: Experiences of Austrian mothers with mobility or sensory impairments during pregnancy, childbirth and the puerperium: A qualitative study. *BMC Pregnancy Childbirth*, 2017; 17(1): 201
23. Herwig A, Weltermann B: Study protocol for a matter of heart: A qualitative study of patient factors driving overuse of cardiac catheterisation. *BMJ Open*, 2017; 7(9): e017629
24. Tomandl J, Book S, Gotthardt S et al: Laying the foundation for a core set of the International Classification of Functioning, Disability and Health for community-dwelling adults aged 75 years and above in general practice: A study protocol. *BMJ Open*, 2018; 8(8): e024274
25. Matic S: German patients turn to Croatia for organ donations. Deutsche Welle 2018. <https://www.dw.com/en/german-patients-turn-to-croatia-for-organ-donations/a-42357468>
26. Caille-Brillet AL, Schielke CKM, Stander V: Bericht zur Repräsentativstudie 2016 “Wissen, Einstellung und Verhalten der Allgemeinbevölkerung zur Organ- und Gewebespende”. BZgA-Forschungsbericht. Köln: Bundeszentrale für gesundheitliche Aufklärung. 2017. [https://www.organspende-info.de/sites/all/files/files/Forschungsbericht_Organspende_2016_final\(2\).pdf](https://www.organspende-info.de/sites/all/files/files/Forschungsbericht_Organspende_2016_final(2).pdf) [in German]
27. Schulte K, Borzikowsky C, Rahmel A et al: Decline in organ donation in Germany – A nationwide secondary analysis of all inpatient cases. *Dtsch Arztebl Int*, 2018; 115(27–28): 463–68
28. ONT. Guía de Buenas Prácticas Donación 2011. http://www.ont.es/publicaciones/Documents/GUIA_BUENAS_PRACTICAS_DONACION_ORGANOS.pdf [in Spanish]
29. Kosieradzki M, Jakubowska-Winecka A, Feliksiak M et al: Attitude of health-care professionals: A major limiting factor in organ donation from brain-dead donors. *J Transplant*, 2014; 2014: 296912
30. Pearson A, Robertson-Malt S, Walsh K, Fitzgerald M: Intensive care nurses' experiences of caring for brain dead organ donor patients. *J Clin Nurs*, 2001; 10(1): 132–39

31. Siminoff L, Gordon N, Hewlett J, Arnold R: Factors influencing families' consent for donation of solid organs for transplantation. *JAMA*, 2001; 286: 71–77
32. Ebadat A, Brown CV, Ali S et al: Improving organ donation rates by modifying the family approach process. *J Trauma Acute Care Surg*, 2014; 76(6): 1473–75
33. Long SD, Morgan SE, Harrison T et al: When families talk: Applying interpretative phenomenological analysis to African American families discussing their awareness, commitment, and knowledge of organ donation. *J Natl Med Assoc*, 2012; 104(11-12): 555–63
34. Feeley T, Moon S: A meta-analytic review of communication campaigns to promote organ donation. *Communication Reports*, 2009; 22: 263–73
35. Breidenbach T, Rahmel A, Lingemann M et al: Communicating about organ donation and transplantation: A handbook on theoretical and practical aspects: Deutsche Stiftung Organtransplantation and Slovenija-Transplant DSO; 2016
36. Norris L: *Transplant administration*. Wiley-Blackwell, 2014