

RESEARCH AND PRACTICE OF HEALTH PROMOTION

THE ORGAN DONATION PROCESS: CAUSES OF THE ORGAN SHORTAGE AND APPROACHES TO A SOLUTION

**An analysis of the content and
methods of available studies**

VOLUME 9



Federal Centre for Health Education

BZgA

The Federal Centre for Health Education (BZgA) was founded in 1967 as an authority in the sphere of responsibility of the Federal Ministry of Health and is based in Cologne. In the field of health promotion, it handles both information and communication tasks (education function) as well as quality assurance tasks (clearing and coordination function) at the national and international level.

The information and communication tasks include the provision of information in subject areas with particularly priority as regards health, and also in subject and target group-specific key fields. The current key field, for example, is health for children and adolescents. In addition, the BZgA implements long-term, nationwide education campaigns in the fields of AIDS education, drug prevention, sex education and family planning. The essential tasks of the BZgA in the quality assurance sector include the elaboration of basic scientific principles, the development of guidelines, and the elaboration of market overviews of media and measures in selected fields.

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**An analysis of the content and methods
of available studies**

An expert report by Stefan M. Gold, Karl-Heinz Schulz and Uwe Koch, commissioned by the Federal Centre for Health Education (BZgA)

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Preface

Most people in Germany have a basically positive attitude towards organ donation and only insignificantly fewer of them are willing to donate organs themselves after their death. In contrast, only a small portion of the population possesses an organ donor card, and a major shortage of organ donations still prevails in German hospitals.

Against this backdrop, the Federal Centre for Health Education (BZgA), which has been entrusted by the Ministry of Health with education and information concerning organ transplantation since 1996, commissioned an expert report on the organ donation process. On the basis of international studies, reasons for the organ shortage were to be determined and possible approaches to a solution developed with regard to increasing the donation rate.

The results of this study are now available as Volume 9 of the specialist booklet series "Research and Practice of Health Promotion". In this volume, the authors explain the decisive factors in the decision-making process and examine the studies available on the various aspects in an analysis of content and methods. Building on this, they develop a model of the organ donation process and give their recommendations for future strategies for increasing the organ donation rate. As a supplement and extended approach, this booklet contains in its conclusion the summary of the results of a one-day expert workshop held by the BZgA on 27 March 2001, on which occasion the expert report and the central approaches derived from it were discussed with regard to future measures.

Cologne, August 2001

Dr. Elisabeth Pott
Director of the Federal Centre
for Health Education

Outline of the project

Project title: Expert report on the causes of the organ shortage

Goals:

- Presentation of the psychological basis for the decision to donate organs.
- Analysis of content and methods, as well as an overview of the current findings on various strategies for increasing willingness to donate.
- Development of a process model for organ donation.
- Elaboration of recommendations for future strategies and suggestions for monitoring their success.

Implementation period: January to September 2000

Sources: Literature search in the Medline and PsycLit/Psyndex databases; internal expert discussion; visit to the ONT in Madrid, Spain.

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Contents

Introduction	9
1 METHODOLOGY	11
2 STUDIES ON THE ORGAN DONATION RATE	13
2.1 Studies on the potential donor pool	15
3 THEORETICAL MODELS OF THE ATTITUDE TOWARDS ORGAN DONATION	17
3.1 The individual decision on organ donation	18
3.2 Consent of the relatives to organ donation	24
4 STUDIES ON ATTITUDES TOWARDS ORGAN DONATION	29
4.1 Studies on the attitude of the public	30
4.2 Studies on the attitude of medical professionals	31
5 STRATEGIES GEARED TO THE GENERAL PUBLIC	35
5.1 The effectiveness of mass campaigns	36
5.2 The effectiveness of personal communication measures	39
5.3 New strategies	41
6 STRATEGIES GEARED TO THE HOSPITAL SETTING	43
6.1 The effectiveness of structural improvements	44
6.1.1 Excursion: The Spanish model	48
6.2 The effectiveness of personnel training measures	53
7 MODEL OF THE ORGAN DONATION PROCESS	57
8 THE "STRATEGY ORCHESTRA"	65
9 APPENDIX	73
9.1 Bibliography	74
9.2 Table of empirical studies	80
9.3 Summary of the results of an expert discussion	92

Introduction

For many illnesses, organ transplantation represents the only option for life-saving therapy and a substantial improvement in the quality of life. Since its early days, transplantation has matured from an experimental procedure to a routine method of therapy. However, the capabilities of modern transplantation medicine create not only new hope for many terminally ill patients, but also a number of medical, psychosocial, ethical and economic problems.

The primary obstacle to the performance of transplantations usually lies not in their technical feasibility, nor in surgical mortality or rejection problems, but rather in the limited number of donor organs in relation to the number of patients who could be helped by transplantation. In Germany, approximately 1,000 patients died in 1999 alone while waiting for an organ (DSO, 2000). The organ shortage is compounded by the constant expansion of the indications for organ transplantation that accompanies medical progress. On the whole, the attitude towards organ donation within the population is positive (see below), yet only comparatively few people document their decision in writing or inform their relatives of such a decision. Various aspects play a role in this context, such as the taboo surrounding the subject of death, or the fear, as a registered donor, of being treated merely with a view to organ donation in a situation requiring intensive-care treatment. Thus, when approached to give their consent to donate the organs of the deceased, many relatives are uncertain as to which decision would truly represent the wishes of the deceased.

Informing people about organ donation and organ transplantation is one of the responsibilities of the Federal Centre for Health Education (BZgA) in Cologne. Since 1996, the BZgA has been running a campaign on the topic in the form of TV spots, advertisements in print media, the creation and distribution of brochures and donor cards, regional projects such as "Streetwork for Organ Donation", media contacts and exhibitions addressing the subject. These activities are carried out in close cooperation with numerous professional organisations, such as the German Foundation for Organ Transplantation (*Deutsche Stiftung Organtransplantation, DSO*), the Working Party for Organ Donation (*Arbeitskreis Organspende, AKO*), the Federal Union of German Associations of Pharmacists (*Bundesvereinigung Deutscher Apothekerverbände, ABDA*), the German Medical Association (*Bundesärztekammer, BÄK*), the German Hospital Federation (*Deutsche Krankenhausgesellschaft, DKG*), the German Transplant Society (*Deutsche Transplantationsgesellschaft, DTG*) and patients' associations. Furthermore, the BZgA is engaged in promoting scientific study of the topic and encouraging international cooperation. To this end, an international workshop¹ addressing the topic of a European comparison of education work in the field of organ donation was held in November 1998. The present report was commissioned on the basis of these prior activities of the BZgA.

¹ The results of this expert workshop and an expert report on this topic, commissioned by the BZgA, have been published in the German edition of this specialist booklet series: BZgA (Ed.) (2000): Die Herausforderung annehmen. Aufklärungsarbeit zur Organspende im europäischen Vergleich (Accepting the challenge: A European comparison of education campaigns on organ donation). Köln: BZgA ("Forschung und Praxis der Gesundheitsförderung", Vol. 9).

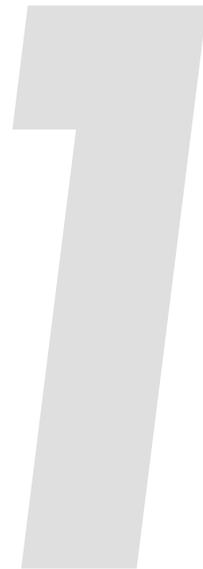
The aim of this report is to present fundamental psychological aspects of a decision in favour of organ donation, to analyse the content and methods of available empirical findings on various strategies for increasing willingness to donate, and to develop an organ donation process model based on the current state of research. Implications for future campaigns and interventions are then to be derived from this model, and suggestions for monitoring success developed. Living donation was not included in the report, since a different set of factors, not only legal but also psychological and organisational in nature, play a role in this case.

After a brief description of the methodology (*Chapter 1*), the first section of the report presents the state of research concerning the size of the potential donor pool (*Chapter 2*), i.e. the maximum number of donors possible based on the frequency of brain death and the currently valid contra-indications for organ donation. Following this, psychological models of the attitude towards organ donation and, most importantly, of the practical implementation of this attitude are discussed, as well as empirical findings on the models, as a theoretical basis (*Chapter 3*). The next part (*Chapter 4*) includes an overview of studies on the attitude of the public and medical professionals towards organ donation. Following this, an overview is given of previous intervention strategies for increasing the donation rate in various countries, as well as their effectiveness. The overview is divided into strategies that are geared to the general public (*Chapter 5*) and strategies for the hospital setting (*Chapter 6*).

Building on the theoretical models from *Chapter 3*, as well as the empirical findings presented, a process model for organ donation is developed in *Chapter 7*. Here, the sequence of events in the donation and transplantation process, from the brain death of a potential donor to the transplantation of organs, is divided into six steps. Influencing factors that may have a bearing on the decision for or against organ donation are deduced for each step. Based on this process model, the last section of the report (*Chapter 8*) recommends a multi-strategy concept ("strategy orchestra") for increasing donation, together with options for monitoring the success of the individual strategies. Finally, the Appendix (*Chapter 9*) comprises a bibliography and a table containing a summary of empirical studies on the attitudes of both the general public and medical professionals towards organ donation, as well as studies examining the strategies for public relations work.

As a supplement and extended approach, this booklet contains in its conclusion the summary of the results of a one-day expert workshop held by the BZgA on 27 March 2001 in order to discuss the expert report and the central approaches derived from it with regard to future measures.

METHODOLOGY



This expert report was produced with the help of a multi-modal strategy: literature review, internal expert discussion; a visit to the Organización Nacional de Trasplantes (ONT) in Madrid, exchange with national and international institutions in the field of transplantation and an integration of theoretical models.

A total of 177 scientific papers were reviewed for this report, of which 119 were integrated into this final version (literature search in the Medline and Psyclit/Psyndex databases). Eight empirical studies were found concerning assessment of the *potential donor pool* and evaluated according to methodological aspects. Based on the department's previous work, a further literature search was initiated regarding the elaboration of the *theoretical models* and the empirical evidence concerning the attitude towards organ donation and its translation into action. Available models were compared with the findings and modified where necessary. A total of 26 studies on the *attitude towards organ donation* among both the general public and medical professionals were included in the report. 44 studies were reviewed which scientifically examined *various intervention strategies*.

Based on preliminary work of the BZgA and on the results of the international workshop held in 1998, possible strategies for increasing the organ donation rate were divided into two categories: measures geared to the general public and measures which concentrate on hospitals and medical professionals. These were categorised according to content, evaluated and grouped as follows:¹

- Intervention strategies for the general public:
 - Campaigns;
 - Lectures and classes;
 - Donation incentives.

- Intervention strategies for the hospital setting:
 - Structural improvements;
 - Staff training.

Furthermore, additional information was collected through national and international contacts with the DSO (Germany), Eurotransplant (Leyden, The Netherlands), and UNOS (USA), as well as through a visit to ONT, the Spanish transplantation organisation, in Madrid during July 2000 (see *Excursion 6.1.1*).

In the next step, a process model was developed based on the study results collected. Finally, this model was used to develop outlines of possible strategies for increasing the organ donation rate, and options were proposed for monitoring their success.

¹ A method-oriented evaluation of the studies (design, intervention and sample size) is also to be found in *Section 9.2* in the Appendix.



STUDIES ON THE ORGAN DONATION RATE

A total of 1,039 organ donations were performed in Germany in 1999 (DSO, 2000). This corresponds to an organ donation rate of 12.7 donations per million population (pmp)/year. The differences between the various Federal States are considerable in this context. Although a comparison of the results from the city-states with those from the larger states can only be very limited, a considerable discrepancy can be seen in the level of organ donations performed, e.g. between Mecklenburg-Western Pomerania (27.4 pmp) and Saxony-Anhalt (8.3 pmp). Brandenburg achieved 13.5 pmp without having its own transplantation program. However, the interpretation of these differences is restricted by possible differences with regard to the incidence of death following acute brain damage, the conditions surrounding the death, and damage to the organs due to pre-existing factors or causes which arose in the course of illness and treatment. In order to record such variables, the DSO has launched a representative, epidemiological study (DSO, 2000).

In an international comparison, Germany (12.7 pmp) is considerably behind the leading countries, such as Spain (33.6 pmp), Austria (25.9 pmp) and Belgium (25.2 pmp) (Mate-sanz/Miranda, 2000). The different legal basis in Germany (informed consent) compared to Spain, Belgium and Austria (presumed consent) is often mentioned in this context. In Spain, however, the procedure actually adopted in practice also adheres to the principle of informed consent (Cohen/Wight, 1999). Moreover, the fact that the DSO region of Lower Saxony/Eastern Westphalia, with a population of 6.8 million, achieved an organ donation rate comparable to that of Austria (21 pmp compared to 26 pmp), despite the legislation concerning informed consent effective in Germany (Gubernatis, 1999), appears to contradict the suggestion that the legal foundation has a strong influence on the situation.

2.1 Studies on the potential donor pool

The search for the reasons behind the organ shortage is also connected to the question of the size of the possible donor pool, i.e. the number of organ donors that could be achieved in the optimum case. Various authors have attempted to estimate the size of the donor pool using different methods (Miranda/Matesanz, 1996). In this context, there are various definitions of the concept of the donor pool. In the present report, the pool of potential donors is defined as number of brain-dead patients. The authors have already excluded cases with medical contra-indications from this number, which is why the term "medically suitable donors" is used here for distinction (see also *Table 1*). The "Detection rate" column in *Table 1* represents the percentage of retrospectively identified, suitable donors who were recognised as such and reported by the personnel of the individual hospitals.

Garrison et al. (1991) retrospectively examined 32,562 deaths in Kentucky and arrived at a number of 173 medically suitable donors (corresponding to 50.8 pmp). Of these suitable donors, however, only 38 actually became organ donors, while the donors were not discovered as such in 29 of the cases and the family refused to consent to donation in 92 cases. The high number reported by Bart et al. (1981) can be ascribed to calculating the number of available kidneys per million population in this study, so that the number of medically suitable donors would be 55 pmp. In a study covering a period of 20 months, Siminoff et al. (1995a) prospectively found a potential of 64.5 pmp for this period. In an examination of the records in 69 and 89 hospitals (in the years 1990 and 1993 respectively) in various regions of the USA, Gortmaker et al. (1996) estimated the number of medically suitable donors at 55 pmp in a projection for the entire country. This number varied little between the two surveys conducted at a two-year interval. Evans et al. (1992) examined all the deaths recorded by the National Center for Health Statistics in the years 1988-89. They arrived at the conclusion that between 6,900 and 10,700 donors are possible each year, depending on the restrictiveness of the selection criteria - severe cranial trauma clearly recognisable based on the medical records (lower limit of the estimate), or less clear signs of brain death (for estimating the upper limit). This would correspond to a donor rate of between 28.5 and 43.7 pmp. Nathan et al. (1991) adopted a similar procedure for their estimate, with the result that a donor rate of between 38.8 and 55.2 pmp could be expected, depending on the strictness of the criteria.

Two studies are available from Spain. On the basis of data from seven hospitals in Catalonia, Espinel et al. (1989) estimate the number of brain-dead patients medically suitable for organ donation at approximately 40 pmp. The detection rate here was 92%. Six years later, Aranzabal et al. (1995) indicated the potential to be approximately 53 pmp.

If a potential donor is not recognised as such, the option of donation is lost without further examination of possible medical contra-indications or request for consent to donation.

Therefore, the detection rate was also examined in many studies. As can be seen in *Table 1*, the findings fluctuate considerably between 92% and 52%.

Study	Time frame	Country	Medically suitable donors (pmp/year)	Detection rate
Bart et al. (1981)	1979	USA	110*	-
Nathan et al. (1991)	1987	USA	38.3-55.2	52%
Garrison et al. (1991)	1988	USA	50.8	83%
Siminoff et al. (1995a)	1991-92	USA	65.4**	92%
Gortmaker et al. (1996)	1990-93	USA	55	73%
Evans et al. (1992)	1988-89	USA	28.5-43.7	-
Espinel et al. (1989)	1987	Spain	40	92%
Aranzabal et al. (1995)	1993	Spain	53	90%

* Refers to the number of available kidneys per million population (i.e. 2 per donor) and thus corresponds to 55 donors pmp.
 ** The donor rate refers to a period of 20 months.

Table 1: International comparison of the medically suitable donor potential and donor detection rates

The potential can thus be estimated at a total of approximately 50 pmp. It must be remembered, however, that a refusal rate of 0% is assumed in these figures, which is not realistic. The refusal rate in Germany was 37% in 1999 and is thus increasing in comparison with the previous years 1997 (29.2%) and 1998 (32.5%) (DSO, 2000). Refusal rates of between 24% and 26% in Great Britain and Spain (Stewart et al., 1994; Matesanz/Miranda, 1997) and up to 73% in The Netherlands (Kranenburg et al., 1998) have been reported in other countries as well. Given a detection and referral rate of 100%, a decrease in the refusal rate by families to 20% and an incidence of cardiac arrest in the donor of 2%, Spain's Organización Nacional de Trasplantes (ONT) assumes an achievable donor rate of 40 pmp per year.¹

The studies presented here suggest that a significant portion (8 to 50%!) of the potential organ donors are not even discovered and are thus lost for possible donation, even before the clarification of medical contra-indications or the request for consent from the family. According to the latest DSO data (2000), 57.3% of all registered donors actually become organ donors. The primary reason for loss of potential donation following detection is refusal by the family (37%).

1 Personal communication, Dr. B. Miranda, Madrid, 11 July 2000.



THEORETICAL MODELS OF THE ATTITUDE TOWARDS ORGAN DONATION

Radecki and Jaccard (1997) distinguish between two types of decision to donate: on the one hand, people's *individual decision* about donating their organs after death and, on the other hand, the completely different process involved in the *consent decision* of the relatives regarding donation of the deceased's organs. In the latter case, a further distinction is made, depending on whether or not the deceased's wishes are documented or otherwise known. This differentiation has been adopted below.

3.1 The individual decision on organ donation

As regards the individual decision, a person's beliefs (religious and cultural beliefs, knowledge, altruistic and normative beliefs) form the basis for the attitude towards organ donation (Radecki/Jaccard, 1997). These beliefs encompass the perceived advantages (such as helping others), disadvantages (such as causing disharmony among one's own family or placing the family under strain) or consequences (such as the personal examination of one's own mortality) of the decision to become an organ donor (Radecki/Jaccard, 1997). There are positive and negative influences in all areas.

The attitude constitutes one of the predictors for the documentation of a person's wishes (Winkel et al., 1984), which can be expressed in the act of completing and signing a donor card, enrolment in a register, or in discussions with relatives.

Fundamental factors of attitude

Aspects of *religion* or *cultural affiliation* were primarily examined in the USA and will not be discussed in depth here. An extensive overview can be found in the review by Radecki and Jaccard (1997).

Knowledge

In a study of a total of 481 students and a random sample of 465 residents of a small town, Horton and Horton (1990) examined the connection between transplantation-specific knowledge and the attitude towards organ donation. Although they found a high level of information regarding the organ shortage, as well as concerning the effectiveness of transplantation or the need for the consent of the deceased or his relatives, significant gaps in knowledge were revealed in other areas. Among these were wrong beliefs, such as that organ donation is rejected by religions (although the Christian religions, as well as Hinduism, Buddhism, Islam [depending on branch] and the Jewish faith officially advocate organ donation as an act of charity), a lack of knowledge concerning the concept of brain death (roughly 80% stated that cardiac arrest must occur in a potential donor), as well as

uncertainty pertaining to the donor card (73% believed that such a document was only valid in conjunction with official registration with the Department of Health) (Horton and Horton, 1990). A generally good level of knowledge correlated significantly with a positive attitude, the carrying of a donor card and the willingness to donate both one's own organs and those of close relatives. On the other hand, gaps in knowledge concerning the three listed areas (religious beliefs, concept of brain death, donor card) had a significantly negative influence.

Misconceptions and fears

Common misconceptions and fears with regard to transplantation were demonstrated in many studies¹: people believed that organs were removed prior to actual death, death was declared prematurely, life support machines were kept running unnecessarily long, the body was severely disfigured by the explantation of the organs, it was possible to recover from brain death, older persons were considered not to be suitable donors, and a person would not receive optimum intensive medical care as a potential donor.

In a qualitative study in the USA, Peters et al. (1996) examined differences between persons who responded in the affirmative to the question "Are you an organ donor?" (donors) and persons who responded in the negative to this question (non-donors). To this end, group discussions were held and later rated (a total of 51 donors and 51 matched non-donors). In the non-donor groups, there was found to be a strong distrust of transplantation medicine, specifically as regards the fairness of organ allocation. Doubts as to the usefulness of transplantation for the recipient were also evident. Furthermore, the non-donors were less willing to accept the concept of brain death. Both groups, on the other hand, rejected not only financial incentives to encourage the family to consent to donation, but also the presumed consent approach, and wished to have more information on the topic.

Such misconceptions are not only negatively correlated with an approving attitude towards organ donation (cf., for example, Peters et al., 1996; Horton/Horton, 1990); it was additionally proved in other studies that improved knowledge could lead to a more positive attitude (cf. Schulz et al., 2000).

Altruistic beliefs

According to present research results, altruistic beliefs are coupled with a greater willingness to donate (see Radecki/Jaccard, 1997). The following views fall into this category: organ donation gives death a meaning and transplantations significantly improve the life of the recipients. In a study by Davidson and Devney (1991), the results of a survey showed that material incentives did not increase the willingness to donate, which underlines the importance of altruistic values.

¹ Cf. Basu et al., 1989; Corlett, 1985; Gallup, 1993; Hessing/Elffers, 1986; Horton/Horton, 1990; McIntyre et al., 1987; Nolan/Spanos, 1989; Parisi/Katz, 1986; Wakeford/Stepney, 1989.

Models of attitude

In addition to the factors discussed above, the model by Skumanich and Kintsfather (1996), based on the Elaboration Likelihood Model by Cacioppo and Petty (1986), indicates that the time and energy spent critically considering the topic ("involvement") plays an essential role in the development of the attitude towards organ donation. According to this theory, the subjective, intrinsic importance of the object on which an opinion is to be formed is of great significance in the development of that opinion. Depending on the degree of involvement, information received is cognitively elaborated (i.e. processed and evaluated) to a greater or lesser degree. When processing topic-relevant information, persons very involved with the topic pay attention to central aspects of the message, such as quality and strength of the arguments. This processing channel is referred to as *central route persuasion*. It is assumed that this central processing leads to lasting knowledge or a change or manifestation of attitude and is closely related to future behaviour. Furthermore, it leads to a more targeted extension of the search for, and processing of, information. In contrast to this, persons who display only a low degree of involvement perceive information peripherally, by the so-called *peripheral route*. They pay less attention to the content of the information than to peripheral stimuli, such as the attractiveness of the "sender". This form of information processing is associated with less persistent attitudes and does not predict future behaviour. Skumanich and Kintsfather (1996) assume that persons who are strongly interested in the topic of organ donation are more likely to display central processing, and thus have a more positive and persistent attitude, and are also more likely to sign a donor card. Empathetic identification with the "victims" (i.e. the waiting patients) also appears to the authors to be important. In social psychology, this is taken to be an essential predictor for altruistic helping (Bierhoff, 1996).

In a study of 169 undergraduates (students in their first-level university studies between 18 and 22 years old), Skumanich and Kintsfather validated their model (see *Figure 1*), which held its ground in an empirical test (multivariate verification of the direct and indirect influences using LISREL analysis).

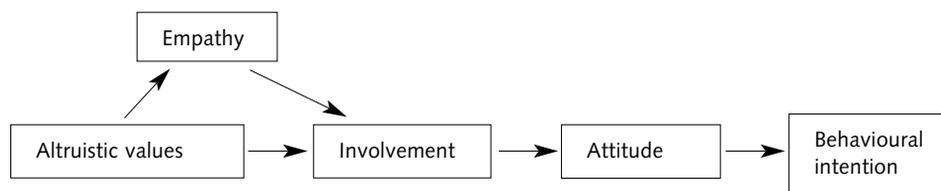


Figure 1: Causal model of willingness to donate organs according to Skumanich/Kintsfather (1996)

The significance of involvement with the topic is also revealed in a survey commissioned by the BZgA in 1999 (Forsa, 1999, see *Figure 2*). The percentage of persons with a positive attitude rose with increasing involvement with the topic, while the percentage of persons with negative attitudes fell. It is also of importance that the percentage of undecided per-

sons among those very involved with the topic is much smaller than among those who had previously been very little involved with the topic. These phenomena can be seen in both active acceptance of organ donation ("I agree to the removal of organs following my death") and passive acceptance ("I have a generally positive attitude towards organ donation").

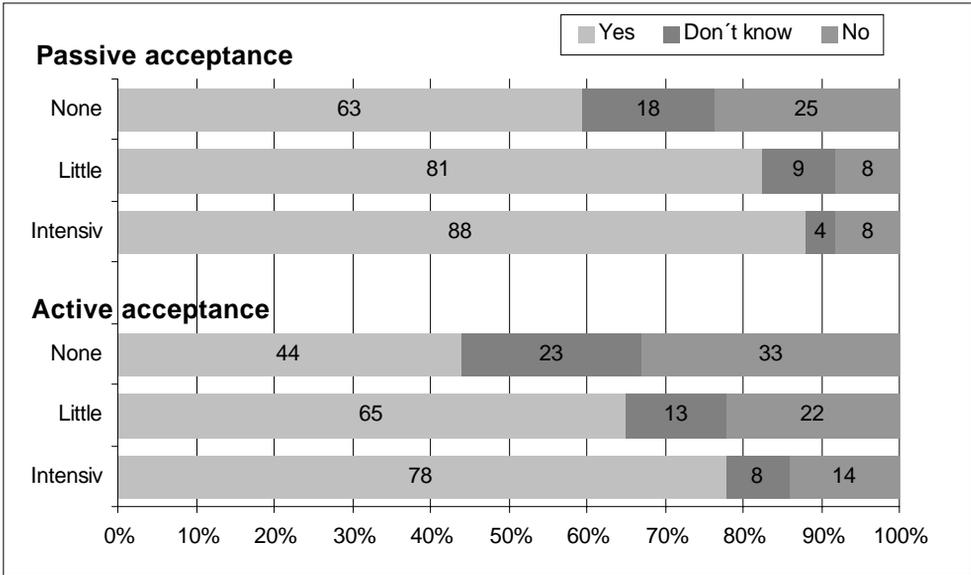


Figure 2: Passive acceptance (top) and active acceptance (bottom) of organ donation as a function of involvement with the topic (none – little – intensive) (Forsa survey commissioned by the BZgA, 1999).

Discrepancy between attitude and behaviour? Phenomena and approaches to an explanation

There is a significant discrepancy between the number of people who state a positive attitude towards organ donation (according to the 1999 Forsa survey, 78% and 63% for passive and active willingness to donate) and the number who possess a donor card (approx. 11%; Forsa, 1999). There are various explanations for this apparent contradiction:

1. Firstly, it is a well-known social-psychological phenomenon that general attitude and intention only concur slightly with corresponding behaviour (Stahlberg/Frey, 1996). Following contradictory research results, the social-psychological question "Can behaviour be predicted by attitude?" was posed in a more differentiated fashion ("Under which circumstances is there a connection between attitude and behaviour?", "Which other factors decide the degree of connection?" or "In connection with which mediating variables do attitudes influence behaviour?" (Zanna/Fazio, 1982).

2. One possible explanation for the low correlation between attitude and behaviour is the "correspondence hypothesis" of Ajzen and Fishbein (1977), according to which a close link between measured attitude and behaviour is only to be expected if both concepts have been formulated in a comparably specific manner. According to Ajzen and Fishbein, both attitudes and behaviour can be described with reference to four different aspects:

- *The action aspect* (Which behaviour is to be examined? For example, electing someone, helping someone or purchasing something),
- *The target aspect* (At which target is the behaviour aimed? For example, a politician, a friend or a product),
- *The context aspect* (In which context is the behaviour performed? For example, within a totalitarian or democratic system, publicly or privately, with an empty or well-filled wallet),
- *The time aspect* (At which point in time is the behaviour to be performed? For example, next spring, immediately, or within the next two years).

Attitudes are often recorded in a very general manner, covering only the action and target aspects, while behaviour is usually measured very specifically on all four levels. Applied to the example of the attitude towards organ donation, this means that the question "How do you feel about organ donation in general?" or, more specifically, "Would you donate your organs or those of your relatives?" contains merely the action and target aspects. If behaviour is measured via the number of persons possessing a donor card, the context aspect (for example, how obtainable was a donor card and how much is known about its function) and the time aspect play a role. Thus, no close correlation is to be expected according to the correspondence hypothesis. Operationalisation via the organ donation rate is even more difficult, since a whole series of further context factors have a decisive influence here (as will be shown in more detail later). The authors' conclusion is, however, not that global studies of attitude would not be useful. If behaviour is measured in a similarly global fashion, a significant connection may also be found (Fishbein/Ajzen, 1977). Thus, for example, a closer relationship would be expected if a particular behaviour consisting of many different behavioural patterns (such as looking for information on organ donation, having discussions with friends and family, signing a donor card, etc.) were to be studied.

3. Cacioppo and Gardner (1993) point to a further explanation. In their review, they come to the conclusion that attitude towards organ donation is not a one-dimensional construct, but is rather determined by the interaction of two uncorrelated, i.e. mutually independent, dimensions. On the one hand, there is what is known as "pro-donation", which is primarily influenced by personal satisfaction, belief in the humanitarian benefit of organ donation and feelings of pride from being a donor. On the other hand, the negative dimension is determined by fear of mutilation of the body or of receiving only second-rate medical care as a potential organ donor (Parisi/Katz, 1986). If the general public is asked about its attitude towards organ donation, only one aspect will be depicted. An action which can be seen as a step towards organ donation (for example, obtaining and signing a donor card)

requires not only a high level of the "pro-donation" dimension, but also low level of "anti-donation" sentiments. The authors were able to empirically verify that, in the case of a high level of both dimensions, the negative dimension predominates (Parisi/Katz, 1986).

4. A fourth explanation refers to practicability. It can repeatedly be seen that great uncertainty exists as regards how to obtain and complete a donor card (cf. Forsa, 1999). 58% of the respondents stated that they did not know where or how to obtain a donor card. Similar results are also reported by Horton and Horton (1990), who identify insufficient knowledge of how to obtain a donor card as one of the barriers to a willingness to donate (see above). The potential effectiveness of the free distribution of donor cards is shown in studies by Sanner et al. (1995) and Hasegawa et al. (1994): in one region in Sweden, the number of donor card holders was increased nearly threefold just by sending out donor cards by post, an effect which was not significantly boosted by an additional publicity campaign (Sanner et al., 1995; see detailed description in *Section 5.1*). In a survey in Japan, half of the respondents stated that they would sign a donor card if it was distributed free and no registration was necessary (Hasegawa et al., 1994).

Ryan, on the other hand, rejects the hypothesis of a discrepancy and refers to the fact that, averaged across several studies, the number of persons who refused to donate their own organs (or those of their relatives) (22% according to Forsa, 1999, and 25% in the Gallup poll, 1993) corresponds well to the percentage of refusal by families (an average of approx. 30% across various countries).

Development of an integrated model

Figure 3 illustrates an integrated model combining the theoretical approaches presented above concerning the willingness to donate organs (individual decision) and the empirical findings. Based on Radecki and Jaccard (1997), the foundation consists of personal beliefs which, however, in analogy to the two-dimensional model of Parisi and Katz (1986), affect the independent dimensions of "pro-donation" and "anti-donation" in a different manner. While a high degree of altruism and transplantation-specific knowledge is positively associated with very marked "pro-donation", misjudgements and fears lead to an intensification of "anti-donation". Cultural or religious beliefs can be connected positively or negatively to both dimensions, depending on their content. The degree of involvement in the topic (according to Skumanich/Kintsfather, 1996) plays an important mediating role. However, an ultimately positive attitude towards organ donation only develops in cases where there is a high degree of "pro-donation" and "anti-donation" is low. A strong "anti-donation" attitude, on the other hand, hinders the development of a positive attitude (dotted arrow). Whether the attitude is then subsequently put into practice as corresponding behaviour is dependent on various context and time factors (see Ajzen/Fishbein, 1977), which are collectively referred to here as "practicability".

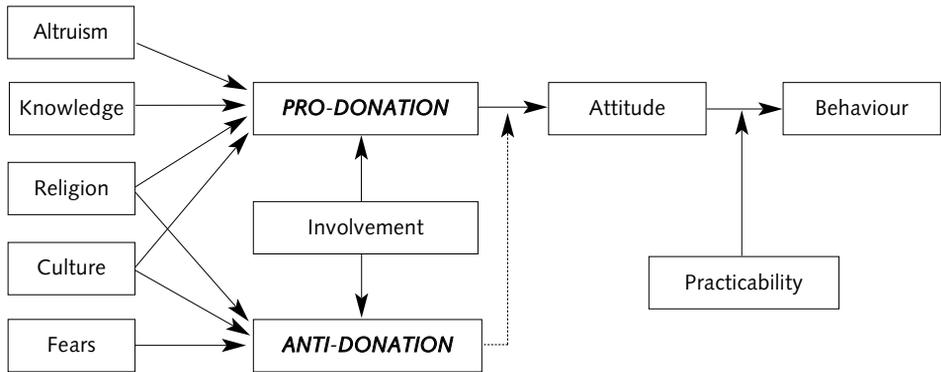


Figure 3: New, integrated model of the individual attitude towards organ donation and its practicability (based on Radecki/Jaccard, 1997; Parisi/Katz, 1986; Skumanich/Kintsfather, 1996; Schulz et al., 2000)

3.2 Consent of the relatives to organ donation

It is part of transplantation practice in Germany and other countries for the relatives of a potential organ donor to always be asked for their consent to organ removal, regardless of whether a donor card or some other expression of the deceased's wishes is available. This also applies to countries where the presumed consent principle applies according to the law.

Basically, a distinction can be made between two scenarios for the relatives' decision:

- the deceased's wish is known,
- the deceased's wish is not known.

According to the model by Radecki/Jaccard (1997), very different factors play a role in the relatives' decision in these two situations.

If the deceased's attitude towards organ donation is positive and known, the decision is in most cases determined by this fact. The most recent empirical data from Spain² also support this, indicating that consent was given in 98% of such cases. If the deceased's attitude was negative and known, the relatives still gave their approval in 22% of the cases. The fact that the known wish of the deceased was overruled in some cases suggests that other factors may also play a role. In this context, for example, a survey of families that had either

2 Personal communication, Dr. B. Miranda, Madrid, 11 July 2000

given or refused consent showed that those who had been satisfied with the emotional support and medical work of the intensive-care staff consented to donation in 90% of the cases, while families who had been dissatisfied in these areas only gave their consent in 50% of the cases³. Furthermore, factors such as dealing with death (*death coping*) and with the stress of having to make a decision (*decision coping*) also have an influence on the family's decision (see *Figure 4*). Thus, it can happen that differences in coping skills or a lacking acceptance of death lead to a slower processing of the decision, and that this delay makes a donation impossible (Radecki/Jaccard, 1997).

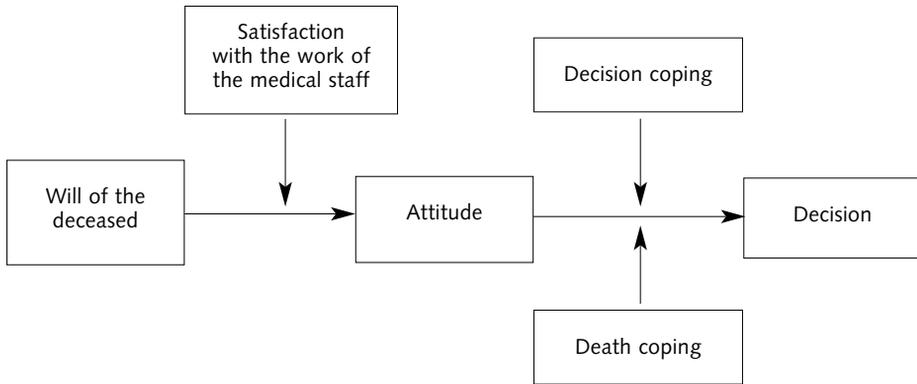


Figure 4: Decision-making model for consent to organ donation when the will of the deceased was known (modified according to Radecki/Jaccard, 1997)

Another model is suggested for cases in which the family members are not familiar with the wishes of the deceased. A number of factors play a role in the development of an attitude towards organ donation or the attempt to discern the decision the deceased would probably have made. Beside their own beliefs and values (analogous to the model of the individual decision: religious and cultural aspects, knowledge, altruism and norms), three further aspects are additionally present here. Firstly, the family attempts to discern the wish of the deceased based on so-called attributional beliefs. This is done on the basis of information regarding the religious affiliation of the deceased, or his or her attitude towards medicine (Harris et al., 1991), as well as the deceased's assumed willingness to help others (Tymstra et al., 1992). The relatives' attitudes towards medicine (beliefs about medical profession) also play an important role. Contributory factors in this context include the experience with the intensive-care staff during the medical treatment, as well as the understanding of all aspects related to organ removal. Some studies have shown the importance of comprehensible information about organ donation and brain death with regard to a family's decision (overview in Radecki/Jaccard, 1997). The emotional support per-

³ Personal communication, Dr. B. Miranda, Madrid, 11 July 2000

ceived by the family (beliefs about emotional support) is also involved. According to Cerney (1993), various aspects play a role here. A family that has the impression that its feelings and mourning are understood, and that the deceased received the best possible medical care, is more likely to consent to donation. Moreover, it is said to be important that the family is given all the necessary information, as well as appropriate time and opportunity to take undisturbed leave of their deceased relative. According to Cerney (1993), more subtle emotional reactions, such as unresolved conflicts with the deceased, can also play a role.

Just as in a decision made with knowledge of the deceased's wishes, individual differences among the relatives also play a role. Depending on how well they are capable of coping with the news of the death and their subsequent mourning (*death coping*) and how well they are able to make a decision in this difficult situation (*decision coping*) the consent to organ donation will be more or less probable (*Figure 5*).

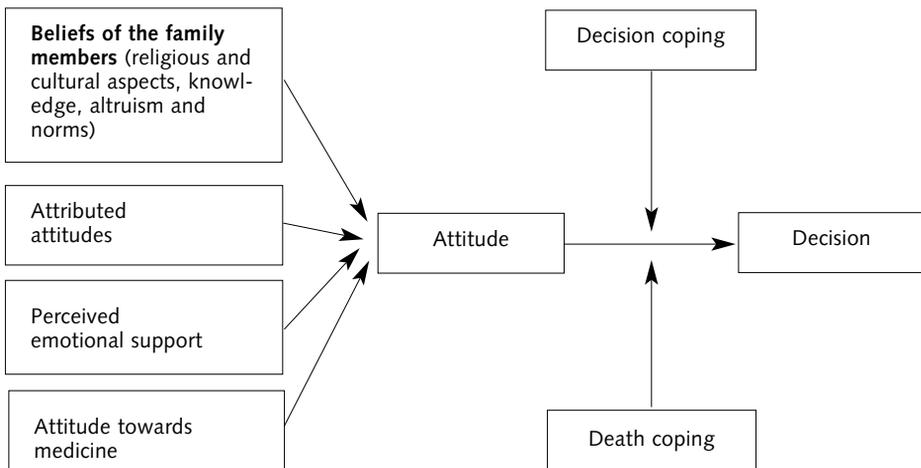


Figure 5: Decision-making model for consent to organ donation when the will of the deceased was not known (modified according to Radecki/Jaccard, 1997)

In 30 to 60-minute telephone interviews, DeJong et al. (1998) studied a total of 164 relatives of medically suitable organ donors within 4 to 6 months of the death of the family member. 102 of the respondents had consented to donation, while the remaining 62 had refused organ donation. The response rate in the subgroup of non-donor families was significantly lower than that of the donor families (58% vs. 76%). Differences were seen with regard to ethnic affiliation (donor families were more frequently white), nationality (donor families were more likely to be US citizens), education (higher in donor families) and income (also higher in donor families). The wish of the deceased to donate his or her organs was three times as frequently known to the relatives of those who donated (33% vs. 10%). On the whole, however, approximately $\frac{2}{3}$ had never talked about the subject with the de-

ceased. Moreover, the donor families themselves had a significantly more positive attitude towards organ transplantation. On a rating scale which assessed the perceived quality of the medical intensive care, the non-donor families were found to be far below the donor families, i.e. they less frequently answered "yes" to statements such as "My relative received the best possible treatment" (70% vs. 93%) or "The staff took the time to answer my questions" (77% vs. 95%). While 83% of the donor families stated that the request for organ donation was made at an appropriate time, this was only so in 46% of the cases in the other group. Only 56% of the families who had rejected donation stated they felt they had been given enough time to understand the concept of brain death before they were supposed to decide (83% in the donor group). This is also reflected in the fact that the relatives of the donors better understood the criteria and displayed a greater knowledge of the subject in the survey. A total of 94% of the donor families stated they would make the same decision again, as opposed to 66% of the families who refused their consent. All the differences reported here were statistically significant.

Burroughs et al. (1998) conducted a telephone survey of 225 family members who had either given ($n = 159$) or refused ($n = 66$) their consent to the donation of organs of a deceased relative. Donor families had a higher standard of education and more often carried a donor card themselves. It was also seen that the topic of transplantation was discussed significantly more frequently in donor families while the deceased was still alive. The focus of the study was the later satisfaction of families with their decision. It was found that a total of 21% would not make the same decision again. Married relatives were more satisfied, and the kind of hospital also played a role. The satisfaction with the decision and its stability were significantly greater in smaller hospitals than in university clinics. Satisfaction with the psychosocial care provided by the staff during the intensive-care treatment had a positive influence on the stability of the decision.

4

STUDIES ON ATTITUDES TOWARDS ORGAN DONATION

4.1 Studies on the attitude of the public

Surveys concerning the topic of organ donation and transplantation have been performed repeatedly in recent years. In the survey conducted by Forsa on behalf of the BZgA in 1999, telephone interviews were used to collect opinions and attitudes concerning various aspects of transplantation medicine using a systematic, random sample of 1,003 persons over the age of 18 years in the Federal Republic of Germany. According to this survey, the passive acceptance of organ donation is 78%, somewhat higher than active acceptance (63%)¹ (see Figure 6). It is striking to note that two-thirds of the respondents stated that they had hardly concerned themselves with the topic, if at all. This appears all the more important, since involvement with the topic is a decisive mediating variable: the passive and active acceptance in persons who had intensively involved themselves with the topic was 88% and 78%, respectively. In comparison, the values for those who had not yet concerned themselves with the topic at all lied at 63% and 44%. While 30% of the first group possessed a donor card, this number dropped to only 1% among those who were little involved with the topic. On an average of the total sample, 11% of the survey participants stated that they carried a donor card. Compared to involvement with the topic, differences in various groups defined by age or education level, as well as gender, or differences between the old and new German states, were all of less significance.

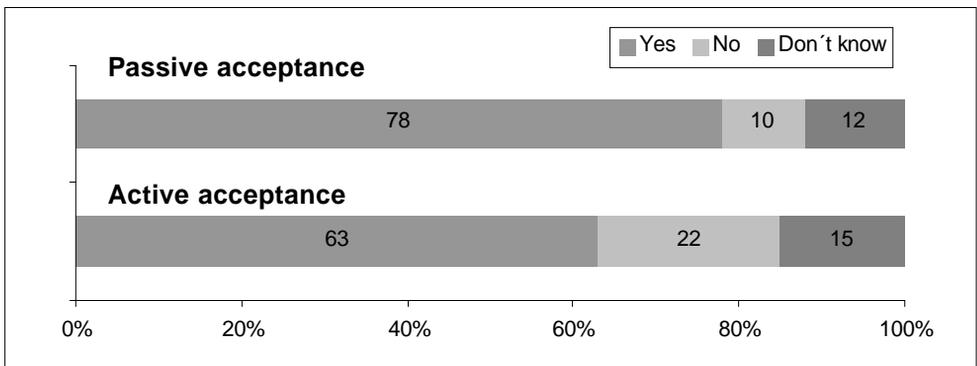


Figure 6: Percentage of positive, negative and neutral responses to the statements "Have a generally positive attitude towards organ donation" (passive acceptance) and "Would donate my organs after my death" (active acceptance) (Forsa, 1999)

In a heterogeneous sample of schoolchildren, doctors, nurses and office employees (a total of 406 persons), Schütt and Schroeder (1993) found an acceptance rate of 100% with regard to both willingness to donate and to the desire to receive an organ in a situation of need.

¹ According to the latest representative survey (N = 1,000, aged 14 and older) carried out in November 2000, passive acceptance has risen by 4% to 82% compared to 1999, while active acceptance has increased from 63% to 72% (Forsa, 2000)

The Gallup poll from the USA (1993) showed a general (passive) acceptance of organ donation of 85%. In response to the question whether they would donate their own organs (active acceptance), 25% ruled out donation, of whom a good half could not offer any reasons.

In addition to the two large-scale surveys quoted above, there are several smaller studies² from various parts of the world concerning the attitude of the general public towards organ donation. These studies often examine the influence of important local religious or societal aspects, which are not to be addressed here. In general, it can be said that the majority votes in favour of organ donation, the proportion usually being above two-thirds.

The influence of age on the attitude towards organ donation becomes clear in a study by Roels et al. (1997) from Belgium. In 1,306 persons from three generations, the authors were able to show that not only the active, but also the passive acceptance rate declines with increasing age.

4.2 Studies on the attitude of medical professionals

Medical professionals, especially intensive-care staff, play a decisive role in the recruitment of donor organs. Doctors and nursing staff are the ones who accompany the relatives while the patient is still alive and later also bring the news of his or her death. The question concerning organ donation is ultimately also posed by them. It has been stated in many reports that doctors and nurses often feel overtaxed by this task and that they are greatly stressed by having to make the request for a donation almost immediately after delivering the news of the death (Schweidman/Muthny, 1997; Blok et al., 1999; Gubernatis et al., 2000). The avoidance or merely superficial handling of this aspect could be one of the factors responsible for a relatively high refusal rate.

Due to their key position in the organ donation process, doctors and nursing staff, and often also the medical students who represent the next generation of those working in this field, have been surveyed in a number of studies concerning their attitude towards organ donation. However, there are hardly any representative surveys and the selected samples serving as the basis mean the acceptance rate is probably overestimated.

Weber (in print) surveyed a large sample of doctors from different disciplines at an interval of 5 years (759 doctors in 1994/95, 500 doctors in 1999; response rate: 50% and 56%,

² Cf. Cheung et al., 1998; Pike et al., 1992; Rene et al., 1995; Schutte/Kappel, 1997; Davidson/Devney, 1991; Dominguez et al., 1991; Martinez et al., 1991; Peters et al., 1996; Amir/Haskell, 1997

respectively). Compared to the general public, doctors significantly more frequently advocated organ donation (passive acceptance 91% and 89%) and four times as frequently possessed a donor card (40% and 38%) in both the 1994/95 and 1999 results. The percentage of respondents who believed that an organ trade existed in Germany was high, although it fell significantly over the observation period (from 58% to 46%). However, the individual willingness to donate (active acceptance 84% and 74%) and the belief that organs were distributed fairly (51% and 41%) also showed a decline. The willingness to donate was substantially influenced by the attitude concerning the certainty of medical treatment in case of an accident or illness, as well as the fairness of allocation. On the other hand, age, gender or discipline, personal experience with dialysis patients or psychological stress in caring for potential donors all had no influence. Weber and Canbay (1999) published the results of a survey which included the 759 doctors from the 1994/95 survey (see above), as well as a further 820 nursing professionals. On the whole, they also found a generally positive attitude and greater willingness to donate as compared to the general public in this supplementary study.

Similar results were reported by Gaber et al. (1990) following a survey of 766 hospital employees other than doctors in Memphis, as well as by Minz et al. (1998) in a survey of 204 doctors and nurses in India. The passive acceptance of organ donation is above 70% in each study, although the willingness to donate one's own organs was considerably lower (45% and 59%).

Prottas and Levine Batten (1988) examined a large, heterogeneous sample ($n = 2,323$) in the USA (246 neurosurgeons, 222 administrative employees, 227 nursing directors, 878 intensive-care nurses, 750 public sample). They found generally strong acceptance of organ donation ($> 90\%$ in all groups), while acceptance among the general public was "only" 72%. Doctors showed great unease with regard to dealing with donors' families. The attitude of the senior physician of a ward had a considerable influence on the attitude of his or her co-workers. Furthermore, the authors were able to show that those doctors and nurses whose sphere of responsibility within their professional activity included organ donation were most likely to actively participate in the organ donation process.

Siminoff et al. (1995b) surveyed a total of 1,797 employees in the USA who had a direct, professional involvement with organ donation (doctors, nurses, social workers, clergymen). It was found that over 50% of the respondents had signed a donor card, a percentage which is considerably higher than that of the general public in the USA (28% according to the results of the 1993 Gallup poll). Moreover, the authors found that, the more positive the attitude towards organ donation was, the more likely it was that the conversation with the relatives would be actively sought and a higher consent rate achieved. Despite this, the majority did not feel sufficiently skilled to hold the conversation. The results of Gaber et al. (1990), again a North American study of 765 health care professionals other than doctors, are similar. Although a high general acceptance rate was seen (90%), the actual willingness to donate one's own organs (45%) was considerably lower than among the general

public. Of those willing to donate, however, a large majority also possessed a donor card. This suggests a better-founded opinion and corresponding practical implementation of the opinion, which may possibly be associated with the higher level of knowledge among these persons. It is surprising that only 65% of the respondents equated brain death with actual death. This lends plausibility to the uncertainty when talking to the relatives.

In a group of $N = 134$ doctors, Schweidtmann and Muthny (1977) found generally high acceptance of transplantation (93%), as well as strong acceptance of the concept of brain death (96%). It is striking that 96% of the respondents perceived dealing with the relatives as stressful and that 98% felt that appropriate training for this would be important. One possible approach here is the EDHEP programme (see *Section 6.2*), which has also been used in some hospitals in Germany.

Within the framework of the Donor Action programme (see *Section 6.1*), the attitudes of the staff in a total of five hospitals in Spain, The Netherlands, Great Britain and Canada were again examined. On the whole, strong support was seen for organ donation (Wight et al., 1998). 97% believed that organ donation saved lives; the willingness to donate one's own organs was 79%. With respect to the respondents' assessment of their own skills, the authors found high values regarding the provision of comfort and support for the families (70%). The expected degree of skill was much lower for explanation of the criteria of brain death (44%) and for raising the topic of organ donation and the request for consent to donation (38% and 31%). Clear differences were seen in the international comparison. The respondents in Great Britain felt skilled and best prepared for the conversations with the relatives, while their Spanish counterparts gave their skills in this task the lowest rating. This is surprising, considering that the highest donor rate was achieved in Spain. A precise examination of the connection between the self-rated skills and the consent rate achieved has yet to be performed.

Sque et al. (2000) were able to confirm the high acceptance of organ donation among 2,465 British nurses. A total of 74% had a positive attitude, while 10% clearly voted against donation. In a factor analysis, the authors were able to identify various factors which illustrated the nurses' ambivalent attitudes with regard to altruism (value of organ donation for the community, importance of organ donation), as well as their fears (post-mortem mutilation of the body).

In a survey of 83 medical students, Strenge (1996) found great interest in and high general acceptance of donation. However, only 50% were personally willing to donate, and only 4% possessed a donor card. More than half of all the students expressed spontaneous reservations concerning various aspects (criteria for brain death, risk of organ trafficking, etc.).

In a follow-up to this primarily descriptive study, Strenge surveyed a total of 125 medical students in 1998 (73 in their first semester and 52 in their year of practical training). The willingness to donate and the percentage of those possessing a donor card rose in compar-

ison with the first study (willingness rose from 49% to 59%, donor card holders from 4% to 30%). The frequency of confrontation with dying patients in the course of their university education had a positive influence in this context. Reservations concerning the organ donation process were equally frequent in both groups. The concept of brain death was rated as being worthy of discussion in a majority of the responses, the acceptance of the concept of brain death having a strong influence on the overall attitude. The students in their practical year had already discussed this topic with others quite often, while the new students hoped that their studies would aid them in reaching a decision. However, only 27% of the students in their practical year said their studies had helped them in this respect. Two replications of the Strengé studies are available from the neighbouring countries of Austria and Switzerland. With a slightly modified questionnaire, Laederach-Hoffmann and Isenschmid-Gerster (1998) in Switzerland and Bunzel and Smeritschnig (1999) in Austria performed surveys on the topic of organ donation among medical students. Both groups found very strong interest, where an inverse relationship between the knowledge of legal regulations and reservations with regard to transplantation medicine was found in the Viennese sample (N = 290), i.e., the more accurately the students were informed about the valid legal regulations, the fewer concerns they expressed. In the Swiss students (N = 117), it was also seen that, the better informed they were (of various aspects), the fewer reservations they had; however, a total of 50% again stated strong reservations.

**STRATEGIES GEARED
TO THE GENERAL PUBLIC**



5.1 The effectiveness of mass campaigns

Although large-scale campaigns to increase the willingness to donate organs and stimulate discussion of this topic have already been performed in many countries, few of them have been scientifically evaluated regarding their effectiveness.

The most extensive study in this area was performed by Sanner et al. (1995) in Sweden, where a campaign was integrated into a controlled, semi-experimental pre-post design. First, questionnaires were used to record information concerning attitude, knowledge and the number of persons in possession of donor cards in a total of four administrative districts (3 campaign districts, 1 control district; N = 5,600). Later, the following interventions were performed in the campaign districts over a period of 3 months:

- District A: broad information campaign with lectures, TV spots, posters, discussion groups;
- District B: mailing of an information brochure, including an organ donor card which could be filled out;
- District C: both interventions.

In the follow-up assessment, no change in attitude was seen in any of the study districts. The number of persons who signed a donor card, however, had risen in all of the campaign districts. The largest increase was achieved in districts B and C, where the number doubled to above 10%. In contrast, the percentage remained stable at approximately 5% in district A (information campaign only, without brochure) and the control region (no intervention whatsoever) (see also *Figure 7*).

These results indicate that a successful strategy could consist of making it easier for people to put their positive attitude into practice by enclosing a blank organ donor card with the information material, ready to be signed. Sanner et al. come to the conclusion that only the 75% potential donors, i.e. the portion of the total population that has a positive attitude anyway, can be activated and motivated by public campaigns. A change in attitude would be necessary for a further increase. This can only be achieved in the medium or long term and requires a more personal approach to the targeted persons. In the light of the expense of such an undertaking, it would appear to be more cost-effective to concentrate on the large number of persons who already have a positive attitude.

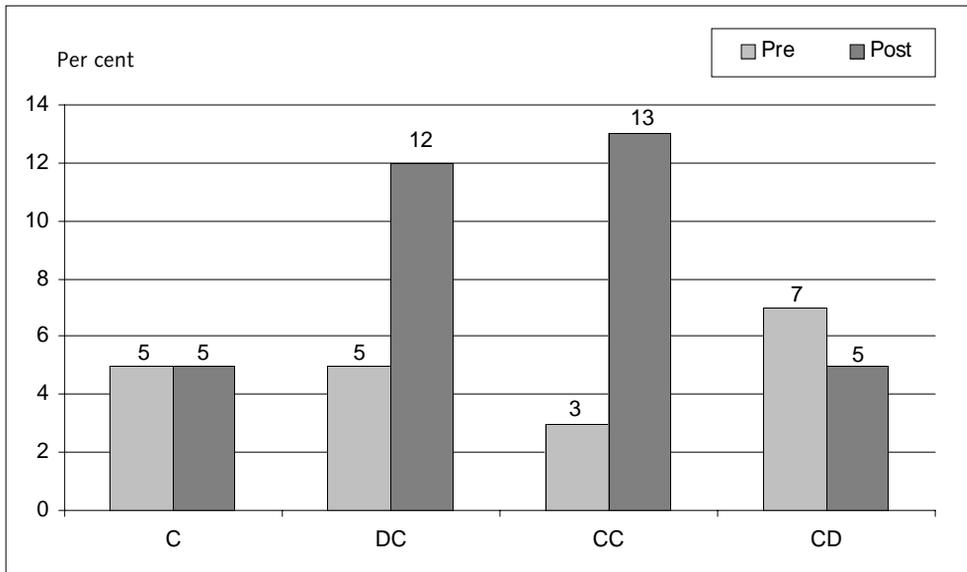


Figure 7: Percentage of organ donor card holders before and after the intervention. C = campaign only, DC = mailing of an organ donor card only; CC = campaign and mailing of a donor card; CD = control district (Sanner et al., 1995)

Other than this study, there are hardly any publications on the effectiveness of mass campaigns that display the same degree of methodical care. In most cases, the authors are content with presenting the campaigns performed and listing the changes occurring over the same period in relation to attitude, the number of donor card holders or the registered organ donor rate. The organ donor rate, in particular, can lead to confusion. This was the reason for a stagnating donor rate being identified in Spain in 1992/93 (Miranda et al., 1995). Only on closer inspection did it become apparent that this was not attributable to ineffective publicity. Rather, tighter laws had resulted in a considerable drop in the number of road deaths, an effect which the (successful) campaign was able to absorb.

In Australia, a series of TV spots on the topic was initiated. These were based on a survey of the population, according to which 89% of the respondents advocated organ transplantation, but only 34% were prepared to donate their own organs and only 17% would release the organs of their relatives for donation. These TV spots were primarily an attempt to counter the low level of discussion of the topic that was found in families. In spite of intensive broadcasts over a period of 12 months, no improvements could be identified in a follow-up study (review in Thomson et al., 1993).

Jacob et al. (1996) evaluated a one-week campaign on the topic of organ donation in the French province of Lorraine. A total of 60,000 posters were hung and 2 million leaflets distributed. Moreover, spots and advertisements appeared on radio, television and in the print media. After three weeks, an independent research group performed a representative sur-

vey among 500 residents of the region. It was found that 46.9% had heard about the campaign, of whom 62.5% stated that they had discussed the topic with their relatives. On the whole, however, the respondents felt poorly informed about the topic (63%) and would have liked a broad-based information campaign at the national level (92%).

In the USA, a major campaign entitled "Share your life ... Share your decision" was launched in 1994 (Servino et al., 1997). In addition to TV and radio spots as well as advertisements in newspapers, Michael Jordan, one of America's most famous athletes, was recruited for the campaign. A poll (Wolf et al., 1997) showed that 59% of the respondents remembered the campaign. Of these, 27% had subsequently reacted to it in some way (conversation with relatives: 12%; signing of a donor card: 10%; search for more information: 1%; other: 4%). A total of 40% of the respondents stated that they had decided in favour of organ transplantation. Of the remaining 60%, only 11% fundamentally rejected the idea. According to their own statements, many had decided positively in favour of donation, but not yet taken any specific action (20%).

In the early 1990s, the Foundation for Organ and Tissue Donation in The Netherlands was commissioned with education and information tasks aimed at promoting organ donation. Although the effects of the campaigns were not systematically studied, the data at least give a few pointers (Persijn/Van Netten, 1997). On the one hand, a significant increase in the use of a telephone hotline, the number of requests for information material and visits to events and exhibitions was seen among the public. This would appear to suggest at least greater involvement with the topic. On the other hand, although an increase in the number of persons possessing a donor card to 21% (!) was achieved, the actual donor rate remained constant.

In 1998, an extensive education campaign was implemented in The Netherlands, using a two-pronged communication strategy. While the Ministry of Health neutrally campaigned for general registration (regardless of whether positive or negative, "neutral message"), organisations from the field of organ donation and transplantation launched "gentle advertising messages", with which positive registration was to be achieved. The heart of the ministry's campaign was a personally addressed letter sent to 12.2 million citizens over 18 years of age. In addition, there were television and radio spots, posters, advertisements and information material. The foundation ran an information centre (answering questions, mailing information material) and organised lectures. The campaign reached 84% of the target group and knowledge concerning the legal regulations (passed in May 1996) rose by 21% to 67% after the campaign. Nonetheless, the attitude of the population could not be improved. On the contrary, the percentage of respondents with a positive attitude towards organ donation fell from 93% to 84%. A total of 36% of the persons who received a letter had themselves registered. Of these, 55% gave their consent to organ donation, 35% refused it, 10% left the decision to the immediate relatives, and fewer than 1% left the decision up to one specific person. On the whole, the people in charge of the campaigns in The Netherlands came to the conclusion that this two-pronged strategy tended more to cause confu-

sion. Apparently, it was hardly noticed that the campaigns were by two separate "senders". Consequently, both mailings were ascribed to the ministry and the impression arose that they were "advertising" for organ donation. Moreover, the letter was received negatively and felt to be impersonal. As a result, a two-phase strategy (only one campaign at a time) is recommended for future campaigns. Furthermore, the mass media are to be involved right from the start and a sufficient budget made available in order to be able to react in the event of a negative response in the press (van Netten, 1999; 2000).

In Sweden, Gäbel and Rehnqvist (1997) examined the outcome of a mailing campaign with information brochures concerning the new transplantation law that came into effect in 1996. A total of 4.2 million households were sent information. Moreover, advertisements were published in newspapers and information material was put out in dispensing chemists and hospitals. 1,000 people were surveyed by telephone before and after the campaign. Prior to the campaign, 79% had a positive attitude towards organ donation, while 12% rejected it. The survey after the campaign showed that 80% of the respondents had read the brochure and 65% had spoken about it with relatives or colleagues. In the nine months following the campaign, 15% of the population registered themselves for the first time (48% consent to removal of their organs in case of their death, 52% refusal).

Callender et al. (1997) examined the effectiveness of a campaign in the USA (Washington, D.C.) which was specially tailored to minorities. A combined strategy of personal address (lectures, information events) by persons of the same ethnicity, consideration of specific fears and prejudices and the involvement of the mass media with positive content concerning organ donation proved to be very helpful. Over a period of 15 years, significant improvements were achieved with regard to attitude, as well as in the actual donor rate and the number of signed donor cards.



5.2 The effectiveness of personal communication measures

As can be seen in the previous section, large-scale campaigns aimed at the general public prove to be difficult. Changes in attitude, and especially in behaviour, are hard to achieve and are often destroyed within a short period of time by "negative" press, such as reports of scandals in the field of organ transplantation (review of a few examples in Ryan, 1997). Furthermore, it is difficult to influence attitudes without personally approaching people (e.g. Stroebe/Jonas, 1996; Sanner et al., 1995). The approach of more specifically and personally addressing a subgroup was developed on the basis of these considerations. This sub-

group was then to spread the message further and have a positive effect on the attitude of the population. Various attempts were made to initiate such a process, especially among children through the use of school lessons. According to Thomson (Thomson et al., 1997), schoolchildren are especially well suited to such a process because they learn quickly, are extensively free of prejudices concerning transplantation medicine and represent an important group with regard to the future, since they will later have an important influence with their attitude as the adult generation of tomorrow. It should, however, be kept in mind that this approach is not aimed at a rapid increase in the organ donation rate. It has more of a long-term perspective and primarily aims to increase involvement with the topic in the population.

In comparison with the evaluation of a mass campaign, target group-specific measures, such as the model of school lessons, offer a research paradigm which is far easier to realise. A number of studies have been performed in this context, primarily in the school setting.

In Australia, an education programme for schoolchildren between the ages of 14 and 18 was developed following the negative results of a survey (see *page 37*). After a multi-stage development process with a few modifications, the programme (10 lessons) was implemented at 600 Australian secondary schools (26%) by 1997. In 1992, a survey was performed to evaluate the programme (Thomson et al., 1997). The lessons were well accepted on the whole. The teacher appears to play a decisive role in this context. Most of the schoolchildren were only able to remember the content if the teacher presented the various parts of the programme in an active fashion and with emphasis. The component of the programme that made the greatest impression on the pupils was the visit by the programme advisor. On the whole, an improvement was seen in the attitude towards organ donation. The pupils' parents stated that the lessons had led to more discussions on the subject at home. The schoolchildren themselves, however, responded that they had discussed the topic more among themselves than with their parents.

Meier et al. (2000) showed in a semi-experimental, controlled study that school lessons can increase knowledge of the topic and simultaneously reduce fear ($N = 67$). This, in turn, leads pre/post to an increase in willingness to donate. In a second paper, the group was able to formulate a theoretical model of factors which influence willingness to donate (Schulz et al., 2000). In addition to these results, it appears important to note that the school lessons were well received by the schoolchildren, an aspect which is of no little significance in the event of large-scale implementation.

Weaver et al. (1999) conducted a comparable study in 212 schoolchildren. They, too, were able to show that transplantation-specific knowledge increased and a more positive attitude became apparent.

Although Zambudio et al. (1998) chose not to include a control group, in spite of a sample of 428 schoolchildren, they performed a follow-up survey three months later. Even if

the study's implications are limited due to the one-group design, the expected increase in knowledge between the pre and post situations was followed by a return to the initial level by the time of the follow-up. This brings up the question as to the stability of the well-documented positive effects of such intervention measures.

A broad-based experiment is currently being launched in Argentina to incorporate transplantation-related content not only into school classes, but also into a number of university degree courses. Results from this study are, however, not yet available (Cantarovich et al., 2000).

A study on the effectiveness of a public lecture on the topic of organ donation and transplantation was published by Harms et al. (1997). However, changes in attitude, and in the intention to sign a donor card or discuss the topic with the family, were only measured after the event, which is a considerable methodological limitation. Thus, the results are to be taken with caution. Still, 66% of those who regarded themselves as having a negative attitude prior to the event stated that they had a more positive attitude following the presentation.

5.3 New strategies

The reimbursement of donors (or their relatives) in various forms (donation incentives) is a relatively new approach in the field of transplantation psychology. Empirical studies on its effectiveness are, however, not yet available. Due to the ethical aspect of this approach, a number of surveys have been performed concerning the moral assessment of such incentives among the general public in the USA. The donation incentives primarily consist of non-material recognition.

Jasper et al. (1999) surveyed 300 jury members of a court (Philadelphia, Pennsylvania) with respect to their attitude regarding such incentives. For the most part, incentives to donate (such as \$1,500 towards the funeral costs, privileged position on the waiting list in the event of requiring a transplant oneself, etc.) were considered to be morally justifiable. The number of non-donors who would donate as a result is higher than the number of donors who would retract in such a case. The applicability of this approach to actual practice remains questionable, however, since only the *willingness* to donate was measured as the dependent variable. This cannot be equated with actual donation.

Another new approach is currently being tested at the John Hopkins University School of Medicine in Baltimore: the anonymous living donation ("altruistic strangers"). In this case, people anonymously donate a kidney. 29 donors registered within just 3 months, 5 of whom have already reached the concluding phase of the donation process. However, no organ has yet been explanted (Ratner et al., 2000).



**STRATEGIES GEARED
TO THE HOSPITAL SETTING**

6.1 The effectiveness of structural improvements

Looking at the latest figures for organ donation and transplantation in Germany (DSO, 2000), a value of 3.9% is listed in the category "Loss of potential donors due to organisational problems". This small percentage is deceptive, however, as the term "potential donors" in this context refers to the number of donors registered with the DSO. The focus in the following approaches for structural and organisational improvement is, however, on increasing the percentage of registered donors from the total pool of *medically suitable potential donors*.

Organisational obstacles, such as poor coordination of the working groups involved in the donation process, exceedingly slow communication and an insufficient number of enquiries at the central office, are frequently mentioned as possible reasons for the low procurement rate in hospitals (Gubernatis, 1999; Gubernatis et al., 2000). Various papers in the field of organ donation have thus examined the effectiveness of structural improvements.

Example: Donor Action

The most extensive such programme is "Donor Action", which arose from an international cooperation project (cf. Cohen/Wight, 1999; Wight et al., 2000). Three international organisations contributed their experience in specific areas of organ donation: the Eurotransplant International Foundation (The Netherlands), the Organización Nacional de Trasplantes (ONT, Spain) and the Partnership for Organ Donation (USA). This programme is designed to assist hospitals in better exploiting their potential for organ donation and improving the support of the affected families at the same time. The procedure is adapted to the specific needs of the individual hospitals. Detailed descriptions of the programme can be found in Wight et al. (2000), Matesanz and Miranda (1996) and in the BZgA's specialist booklet series (2000) and are summarised below.

The implementation of the Donor Action (DA) programme is divided into 6 phases:

- (1) Securing the support and cooperation of the staff,
- (2) Performing a diagnostic review,
- (3) Adapting the programme to the needs of the hospital,
- (4) Introducing/implementing the programme modules,
- (5) Monitoring and evaluating, and
- (6) Programme management at the national level.

(1) Cooperation

The implementation of such a programme is dependent on the support of the staff. For this reason, a multidisciplinary team (DA Committee), consisting of hospital employees and under the direction of an internal coordinator, is established to organise the implementation of Donor Action.

(2) Review

The diagnostic review phase consists of three parts:

- Review of the patient files ("medical records review", MRR) to estimate the difference between the number of potential and actual donors. The aim of this is to determine when and where within the donation process the losses primarily occur.
- Survey of the staff's attitude towards organ donation ("hospital attitude survey", HAS). A simple questionnaire is used to obtain information concerning knowledge, commitment and skills/self-confidence in connection with transplantation-specific topics and tasks, as well as the personal attitude towards organ donation. Furthermore, the degree of training received in this area and the desire for more intensive training are recorded. The response rate should be at least 60% in order to allow valid measurement (Wight et al., 2000). For this reason, the authors recommend first holding a broad-based information campaign on Donor Action within the hospital.
- The MRR and HAS are then evaluated according to prescribed algorithms using a standardised database and previously prepared software. This creates a profile of the organ donation potential for the given hospital. This also forms the baseline for later evaluations of effectiveness.

(3) Adaptation

This phase forms the link between diagnosis and implementation of the intervention. It is in turn divided into three segments:

- Calculation of the potential donor pool based on the MRR data. Evaluation of the reasons for the failure of a donation is also important here.
- Analysis of the HAS data.
- Identification of the areas to be improved. Priorities are determined for the five areas of donor detection, donor referral, family support and communication, donor maintenance and organ retrieval.

4) Implementation

Based on the five target areas named in (3), five intervention modules were developed that can be used singly or in combination. A standard protocol is available for improving detection. In order to improve referral, it is stipulated who has the task of reporting a donor to the responsible transplantation coordinator, when this is to happen and which role the external coordinator is to play during the process. Among other things, the "family support and communication" module involves defining who is to assume responsibility for the sup-

port of the potential donor's family. Important components include, for example, separating the news of death from the request for organ donation, in terms of both time and, possibly, the person performing these tasks. Further modules are geared to the optimum medical treatment of the donor in order to maintain organ function, as well as successful retrieval of the organs. Practice-oriented workshops are available for the aspects of "detection", "communication" and "medical care of the donor".

(5) Evaluation

In the authors' experience, implementation takes between six months and one year. Great demands on time and manpower are involved at the beginning of the programme, but the amount of time and energy required drops greatly as time goes on and improvements are gradually achieved. Following the diagnostic review, the database serves as a monitor for the progress achieved and is used on an ongoing basis for quality control.

(6) National management

The widespread introduction of such programmes should be organised through a management structure, as a variety of tasks arise here: monitoring of effectiveness (collection and evaluation of nationwide data), training and appointment of programme coordinators, recruitment of the members of the DA Committees and the general support of the participating hospitals.

Evaluation of the Donor Action programme

Between 1994 and 1996, such programmes were performed in a total of 11 hospitals in The Netherlands, Spain, Great Britain and Canada (Cohen/Wight, 1999). These pilot studies indicated major potential on the part of these intervention measures as regards increasing the donation rate. In three hospitals in Great Britain, implementation of the Donor Action programme showed impressive short-term effects (Trafford et al., 1997). Within the first six months of the start of the review phase, a 122% increase in organ donations was seen, compared to the same six months of the previous year. One year after the start of Donor Action, 40% growth was noted in the region, compared to the year prior to implementation.

Alonso et al. (1999) published a brief evaluation of the Donor Action programme (one-year catamnesis) at two hospitals in Seville, Spain. The diagnostic analysis yielded the following results: the medical staff displayed little involvement with the topic; furthermore, a low donor identification rate, high refusal rates and in-house organisational problems were also evident. Following these findings, the Donor Action programme was launched and its effects reviewed one year later. The detection rate of potential donors rose from 81% to 98%, and there were no more losses of donors due to organisational problems or incorrectly diagnosed medical contra-indications. The refusal rate among the families had dropped, while the commitment of the staff and their self-perceived skills had increased. This led to an increase in donations from 32% to 44% of the potential donors.

Data for a 2-year study period are also now available from Spain (Wight et al., 2000). In 1995 (prior to the implementation of DA), a retrospective review showed that a total of 21% of the potential donors were not medically suitable. 19% of the suitable potential donors were not identified. The relatives refused their consent in 18% of the cases, while 2% of the donors were lost due to incorrectly diagnosed medical contra-indications and a further 2% due to organisational problems. In 5% of the cases, the donor's cardiovascular function could not be maintained until explantation. Thus, a total of 44% of the potential had been utilised. Following implementation of the DA programme, 33% growth in the donor rate was achieved by the time of 2-year catamnesis, although the number of the potential donors fell by 4% in the same period. In 1997, 98% of the potential donors were identified and there were no losses of donors due to cardiovascular failure or organisational problems. Thus, a total of 65% of the potential was utilised (see *Figure 8*).

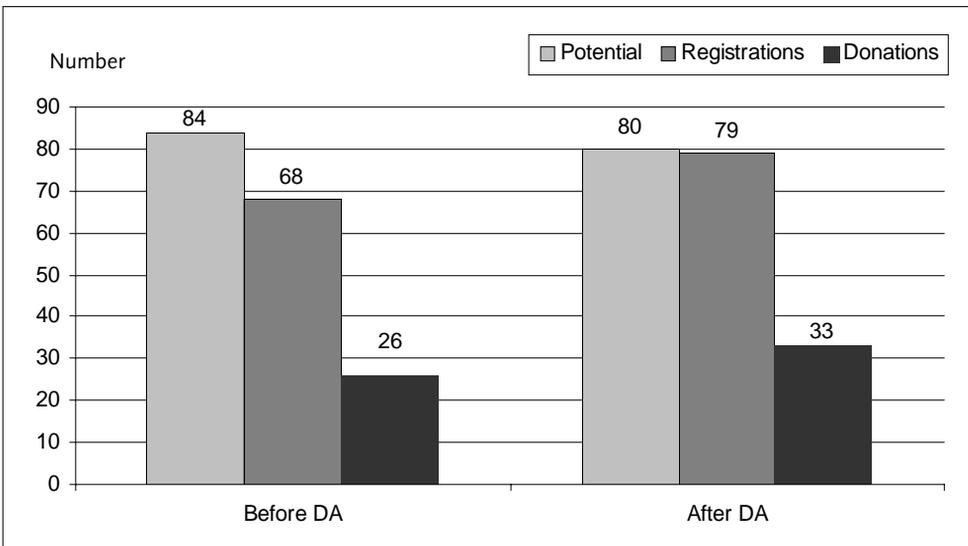


Figure 8: Development of the referral and donation rates over a period of two years in two Spanish hospitals (from Wight et al., 2000)

Example: Coordinators and service centres

A study by Shafer et al. (1997) of 29 hospitals in the USA showed positive effects of a newly created coordinator position. Even though this study is purely descriptive and quite brief, a pre-post comparison still showed that enquiries, donations and the frequency of conversations with the relatives increased by between 80% and 313%. Smaller hospitals appear particularly able to profit from such structural improvements and considerably increase their donation rates.

In Spain, an increase in the organ donation rate from 14.3 pmp to 27 pmp was achieved between 1989 and 1995, primarily through a hierarchically organised coordination structure (national - regional) in which various advisory and support centres were established and "hospital coordinators" appointed in every hospital (see also the excursion in *Section 6.1.1 "The Spanish model"*). While smaller hospitals without their own transplantation programs still only contributed approximately 23% at the end of the 1980s, the number of Spanish organ donors from these hospitals had already risen to 33.6% six years later. Although the greater percentage of the donor organs still comes from maximum-care hospitals (transplantation programme and neurosurgery, Type I), growth in hospitals without transplantation programmes and in those with and without neurosurgical departments (Types II and III) was considerably greater (100% and 300% as opposed to 50%) (Matesanz et al., 1996a). An analysis showed that, with this growth, the Type II and III hospitals had thus already nearly exhausted their capacity in terms of donors per 100 beds (1.3 to 2.2 and 0.3 to 0.7), while the Type I hospitals were still well below the limits of their possibilities (3 to 4 per 100 beds) (Darpon et al., 1995).

In a study of 125 German hospitals, Gubernatis et al. (1997) found increased donation rates following the establishment of a service centre. The service encompassed telephone advice, organisation and coordination, counselling in cases of medical problems, as well as laboratory analyses and brain death diagnostics. Again, primarily the smaller hospitals appeared to profit from the service centre. These results were confirmed two years later (Gubernatis, 1999). In the study region of Lower Saxony/East Westphalia, 84% of the organ donors now come from non-university hospitals; this state has one of the highest donor rates in Germany.

6.1.1 Excursion: The Spanish model

The overall organ donation rate in Spain increased on the national average from 14 pmp (1989) to 27 pmp (1995) (Matesanz et al., 1996b). The latest figures indicate a national organ donation rate of 33.6 pmp (Matesanz/Miranda, 2000). On the whole, the figures vary greatly. Up to 42.3 pmp is achieved in some regions, while only 6.7 pmp is reached in one region in the southern part of the country. The increase is largely attributable to the growing proportion of multiple organ retrievals, from 30% in 1989 to 83.4% in 1995. A marked increase was seen in the percentage of donors above 45 and 60 years of age, while the younger donors became proportionately fewer. The decrease in the number of donors with trauma following a traffic accident (from 43% to 29%) is presumably connected to this, while cardiovascular causes of death rose from 39% to 49%. The majority of the donors are male (approx. 64% in 1995). The rate of refusal by family members remained relatively stable at around 25%. However, there are again pronounced regional differences (between 13% and 42%). While the number of organs removed in transplantation centres remained

relatively stable, the contribution of the smaller hospitals rose from 23.6% to 33.6% (Mate-sanz et al., 1996b).

The Organización Nacional de Trasplantes (ONT)

According to the 1979 Transplantation Act, the statutory requirements in Spain are as follows:

- No compensation of any kind for donation,
- Legitimation (certification) of the centres,
- Prerequisites in the donor, including diagnosis of brain death (in living donation, also prerequisites in the recipient),
- Data privacy,
- Development of a coordination centre.

The ONT was founded in 1989 and is primarily intended to deal with the organisational aspects of organ transplantation. It is involved with the transplantation not only of organs, tissue and bone marrow, but also of stem cells.

Structure and tasks of the ONT

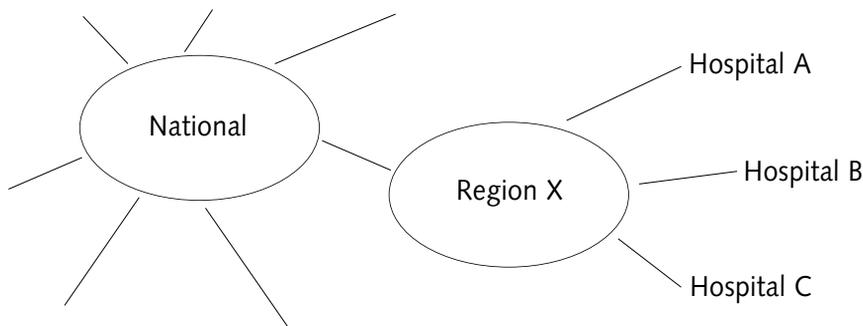


Figure 9: National, regional and local structure of the transplantation system in Spain

The ONT is responsible for the nationwide coordination of organ donation (population of 40 million). It has in the meantime become an official institution that is affiliated to the Ministry of Health and financed by the central government. Its primary task is to increase the organ donation rate. The system is decentralised and has a national coordination centre (Figure 9). The 17 autonomous regions in Spain each have a seat on the *consejo interterritorial* (Inter-Territorial Council, Transplantation Commission), on which the National Transplant Coordinator also sits. This body recommends a president, who is appointed by the Minister of Health. The commission has subcommittees for individual as-

pects, such as continuing education programmes, xeno-transplantation or the transparency of the channels through which the organs pass.

The percentage of administrative functions decreases steadily from the national to the hospital level, while the medical tasks increase (see *Figure 10*).

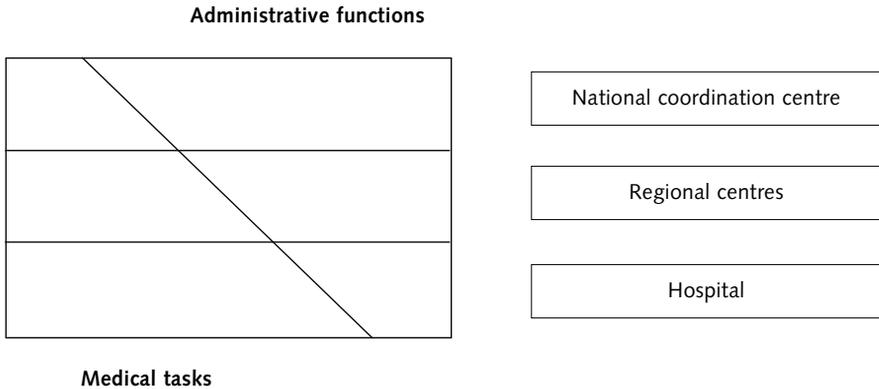


Figure 10: Distribution of administrative and medical tasks at the national, regional and hospital level

Budget of the ONT

The central office in Madrid receives \$1.4 million, from which it must also cover its personnel costs, as well as an additional \$390,000 for holding continuing education events. Each of the regional offices receives a budget of \$30,000 plus \$5,500 per million residents in its catchment area. The exception here is the Catalonian office (Barcelona), which receives a further annual sum of \$40,000 for its function in the exchange of organs with international organisations (such as Eurotransplant).

National coordination

The key person in the Spanish system is the hospital coordinator. As a superordinate agency, the ONT acts amidst the various professionals (surgeons, coordinators, etc.), the national and regional authorities, as well as the other parties involved (press, patients, church, courts, etc.). The national office consists of the National Transplant Coordinator, various health professionals (5 doctors and 8 nurses) and a secretariat (6 posts). The ONT head of office assumes various functions:

- Coordination (multiple organ explantation, maintenance of a waiting list, coordination of the transplantation teams, etc.),
- Data evaluation,
- Development and distribution of the consensus documents,

- Promotion of research,
- Distribution of information to interested groups,
- Public campaigns, cooperation with the media,
- Development of educational material,
- Training courses,
- Foundation of the Spanish Transplantation Society,
- International cooperation.

Regional coordination

Each of the 17 autonomous Spanish regions has a representative on the Transplantation Commission. The Regional Coordinator has the same function at the regional level as the National Coordinator at the national level. They fulfil this function in addition to their professional obligations.

Coordination in the hospital

In contrast to other countries, the Hospital Coordinator (or usually a team of coordinators, see below) is responsible for the *entire donation process* (i.e. legally responsible, delegates the corresponding tasks) and reports directly to the Medical Director. In most cases, these coordinators also continue to work in their normal field. This facilitates a return to their previous occupational situation, should they at some time wish to give up their coordination responsibilities. Between 1989 and 1999, the nationwide number of coordination teams grew from 10 to 139. The number of procedures performed rose from 310 to 1,809. The ONT permanently offers continuing education opportunities.

The coordination teams that handle the hospital coordination function in the majority of cases in Spain consist of a doctor (part-time) and several nurses. Their primary tasks are organ detection and organ procurement (including talking to the relatives). In addition, they are responsible for logistical support, resource management, promotion of organ donation, quality monitoring, forwarding of information to the donor's relatives, contact with the media and scientific involvement with the topic of organ donation (publications, participation in conferences).

Compensation system

The Spanish model is based on the fundamental philosophy that organ donation is a "medical activity" in which many departments of a hospital are involved. Therefore, it must be financed from the hospital's budget, just like any other medical activity. A team of specialists is available on call in the hospitals 24 hours a day.

In order to meet the financial expenditure incurred by hospitals as the result of organ donation, and thus not to expect purely idealistic motivation of the hospitals, a particular sum is paid for each organ donor. This money is divided between the staff involved (salary plus



bonus for on-call duty) and the hospital (donor maintenance, analyses, etc.). For example, the hospital receives \$4,500 for a kidney donor and \$7,000 for a multiple organ donor. If tissue is also donated, a further \$1,400 are received and \$2,250 for tissue only. However, a cost analysis has shown that costs of approximately \$30,000 are incurred by the hospital per organ donor. The coordination teams receive different compensation from region to region¹.

Quality assurance

The ONT has now implemented a three-stage quality assurance programme covering all the country's hospitals and structured according to their location in the 17 autonomous regions. All the forms and steps discussed below are sent to the regional coordination office at specific intervals and from there to the ONT central office in Madrid for evaluation. The Regional Coordinator then receives the feedback and regionally introduces the corresponding measures where necessary.

Step 1

Annual form for recording a hospital's basic data. The number of beds, number of incoming patients and number of deaths are noted for all the hospital's intensive-care units (neonates, children, neurosurgery / multiple trauma, etc.). For the deaths, it is also specified whether brain deaths on a given ward are transferred to other wards (Type B) or remain on that ward until organ explantation (Type A). The form also asks for the number of emergency operations in the neurosurgical department and whether a university programme exists.

Step 2

Every three months, the hospitals submit a form ("datos trimestrales") in which the number of deaths, brain deaths and organ donors is listed for all intensive-care departments.

Step 3

A special form has to be completed for each brain death in a hospital. The series of events from detection to donation is illustrated in a kind of tree diagram and, when appropriate, the cause of the loss of the donor is noted. The first question refers to whether the potential donor was discovered by the coordination team, the second refers to the medical contra-indications. In the third question, an enquiry is made into the reasons preventing donation despite medical suitability (maintenance problems, organisational problems, lack of an appropriate recipient, rejection by a judge, refusal by the family).

1 Except in Andalusia, where each hospital is allowed to devise its own regulations, the same rules apply in all hospitals in a region once the model has been negotiated with the Regional Coordinator. There is a total of four compensation models: a) Fixed model: The team members receive a flat rate; b) Graduated system: There are specific bonuses for defined ranges of donors (e.g. 5 to 6, 8 to 10, 11 to 14, etc.); c) Mixed: Fixed basic sum plus incremental bonuses; d) Variable: Payment is directly dependent on the number of donors. The compensation for a year is calculated in advance, based on the number of donors from a hospital in the previous year.

6.2 The effectiveness of personnel training measures

The introduction of training programmes for intensive-care staff is based on the findings from the studies on the attitude of medical personnel (see *Section 4.2*). Many of those with a position of responsibility within the procurement process feel overtaxed by the conversation with the relatives (Prottas/Levine Batten, 1988) and not sufficiently skilled (Blok et al., 1999).

According to a study of 446 hospital employees in Germany, 93% of the respondents feel severely stressed by the conversation with the relatives (Gubernatis et al., 2000). Those who feel insecure and uncomfortable in conversation with the relatives show a higher refusal rate by the families (Malecki/Hoffman, 1987).

The significance of the conversations in connection with the high rate of refusal of organ donation by the relatives (approx. 30 to 40%, see above) and the self-expressed need for training and support in this difficult and stressful task of the medical personnel are two aspects illustrating the need for personnel training measures. There are relatively few outcome-oriented studies in connection with this finding. As reported above, doctors and nurses often feel insufficiently prepared for this difficult task and would like better training in this area.

Example: European Donor Hospital Education Programme (EDHEP)

The European Donor Hospital Education Programme (EDHEP), developed by Eurotransplant, is one of the most widely spread approaches for the training of intensive-care staff. The first 430 programme participants in The Netherlands stated a high degree of satisfaction. They reported a strong learning effect and lower "barriers" in posing the question of organ donation to the relatives. No differences were seen with regard to the participants' profession, gender or occupational experience. The participants primarily attributed the learning effect to the feedback from the moderators, the practical exercises in role-playing and the video tapes of real interviews (van Dahlen et al., 1996). Similar results were seen in an international comparison of the EDHEP programme (van Dahlen et al., 1999).

The most detailed description and evaluation of an EDHEP training programme available in German is by the research group of Muthny (Muthny et al., 1995; Muthny 1997). Here too, however, here as well, the outcome variables measured were not the change in the procurement rate, but the satisfaction with the workshop and the expectation of skill. The participants' overall rating (N = 184 doctors) was thoroughly positive (92%). 70% expressed a desire for regular refresher courses. Higher expectations of their own skills were seen in



the majority of the participants, and one-third expected a higher rate of consent to donation.

An analysis of the first 204 participants in EDHEP seminars in Israel (Singer/Rachmani, 1997) also yielded significant increases, primarily with regard to transplantation-specific knowledge. A greater feeling of security when talking to the relatives and a further improvement in the already positive attitude towards organ donation were also seen. The authors report that there was no improvement in the (national) donation rate (approx. 9 pmp in Israel), despite these effects, and the refusal rate remained the same at 50%. However, only 12 seminars were held.

Participants from two Spanish hospitals (see Wight et al., 2000) also showed a considerably higher self-assessment in various transplantation-specific tasks two years after the EDHEP-based "Family support and communication" module of the Donor Action programme (see Figure 11). The number of organ donations in these hospitals rose by 33% in the same period. However, the refusal rate remained very stable at 19%, meaning that the achieved increase is more likely to be attributable to an increased detection and referral rate.

EDHEP is now being used in over 30 countries (Cohen/Wight, 1999). Individual reports speak of increased donor rates following its implementation (Fischer-Fröhlich et al., 1999). Controlled evaluations of the effects predominantly concentrated on the satisfaction

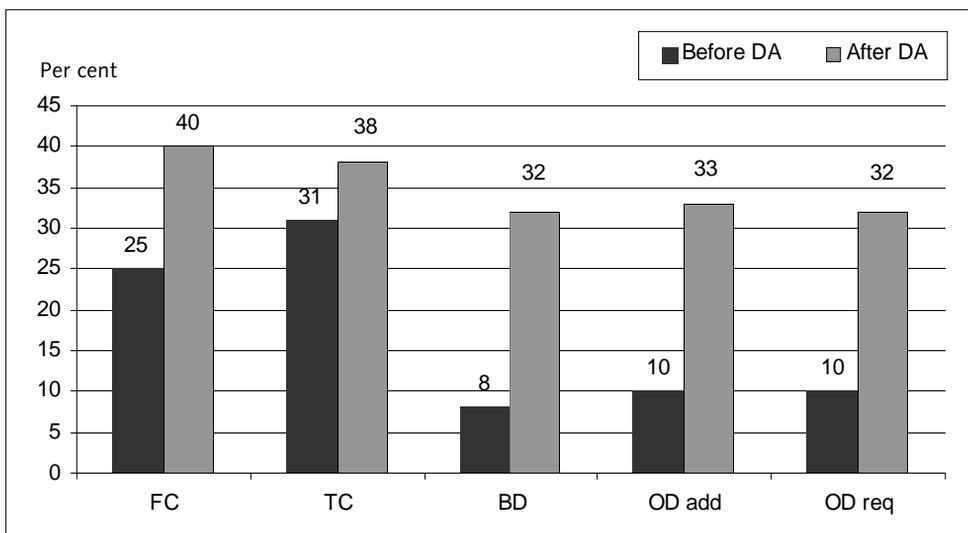


Figure 11: Percentage of positive responses, before and after implementation of the "Family support and communication" module of the Donor Action programme, to the question of self-assessment of skills in providing consolation to the family (FC), informing the transplantation coordinator (TC), explaining brain death (BD), addressing the topic of organ donation (OD add) and requesting consent (OD req) (from Wight et al., 2000)

of the EDHEP participants, as well as their own expected skills in the conversation with the relatives (review in Blok et al., 1999). So far, there are no studies concerning the direct effect of such programmes on the actual donation rate or the consent to donation by the relatives.

Other training approaches

Riker and Wight (1995) held two one-hour training sessions with doctors from intensive-care units on the topics of the role of the doctor in the donation process, contra-indications, legal background¹ and the services offered by the transplantation society. They found a massive increase in the number of conversations with the families (from 1% to 68%) and the consent rate (from 0% to 32%) among the trained doctors as compared to the untrained doctors from the same hospital. However, the very low baseline rate must be considered here, and it should also be mentioned that the effects had disappeared again 6 months later.

Robertson et al. (1998) introduced courses on the implementation of new legal and organisational regulations in 22 hospitals with high donation rates (≥ 10 donors per year). One year after the courses, the number of potential donors identified had risen by 28% in comparison with the previous year, and the organ donation rate by 30%. Smaller increases were seen in hospitals that had previously procured a lower number of organs and had received no training (detection by 16%, donors by 10%).

Further publications on this topic dispense with an empirical section and make do with a description of their tests (Karbe, 1991; Chabalewski, 1997). In a brief description, Neel et al. (1991) describe the effects of an "altruistic marketing strategy" among medical staff, although this is not defined in any more detail. The actual donor rate in California at this time was observed as the outcome. The authors found an increase from 24.5 pmp to 32.6 pmp in this context.



1 The so-called "required request" principle applies in 44 states of the USA, i.e., the request for organ donation is prescribed by law.



MODEL OF THE ORGAN DONATION PROCESS

Against the backdrop of the theoretical and practical models and the summary of the current state of research presented in the preceding sections, a process model for organ donation will now be developed that includes the various factors influencing the organ donation rate. This serves as a foundation for the proposal of possible intervention strategies.

A multi-stage, complex process takes place from the emergence of a potentially suitable, brain-dead donor to the transplantation of the organs (see *Figure 12*). A number of factors influence the individual steps of this process and ultimately determine how many of the potential donors become actual donors. The individual steps can be seen as a series of filters, each of which absorbs a portion of the potential. The influencing variables for each step of the process are compiled and evaluated below.

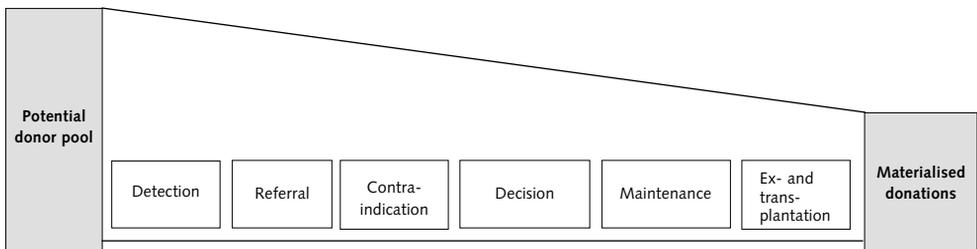


Figure 12: Model of the organ donation process from emergence of a potential donor to organ transplantation

In the model in *Figure 12*, the organ donation process is divided into the following six steps:

1. Detection,
2. Referral,
3. Checking for medical contra-indications,
4. Decision,
5. Maintenance (intensive medical care of the donor to maintain cardiovascular function),
6. Explantation and transplantation.

(1) Donor detection and (2) Donor referral

An essential factor influencing the detection rate of potential donors is the necessary professional qualification of the medical personnel. Even if the actual diagnosis of brain death is later made by others, a potential donor must first be recognised at all. Another significant factor is the staff's motivation to be actively involved in the organ donation process. This motivation is, in turn, determined by personal attitude towards organ donation and transplantation medicine, occupational stress (i.e. does the intensive-care unit staff not already feel overworked and thus fear more work as the result of an organ donor?) and also considerably by the "hospital climate" ("institutional motivation"). The latter refers to guidelines made explicitly, or more frequently implicitly, by the hospital management concerning whether organ donation is to be generally handled supportively or with reservation.

The significance of this factor is revealed in a survey by Gubernatis et al. (2000) of 446 hospital employees. The hospital management's attitude towards organ donation was unknown to nearly 40% of the respondents, of whom 84% would have liked an official position statement on the issue and one-third a written declaration from the hospital directors concerning the importance of the hospital's active involvement in the area of organ donation.

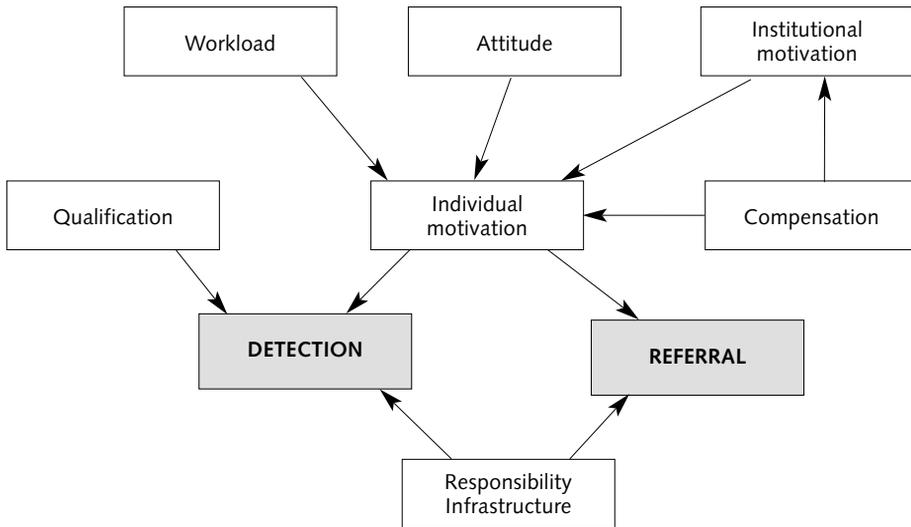


Figure 13: Motivational and organisational factors influencing the detection and referral rate of potential organ donors in the hospital setting

Whether or not an identified donor is also reported to the transplantation coordinator depends on both motivational and organisational aspects. The factor of compensation for extra work also plays a role in the above-mentioned individual and institutional motivation, not only for the individual (in this case the hospital's transplantation officer), but also for the hospital itself. Furthermore, it is important that responsibilities be clarified and that competent contact persons be available quickly and easily. *Figure 13* illustrates the influences on these first two "filters" within the organ donation process. According to this model, compensation for active involvement, meaning reimbursement for working time and material invested, has an indirect effect on the detection and referral rate, primarily by way of motivational factors (individual and institutional).

According to the current state of research presented here, the medical staff's attitude towards organ donation is generally positive, even though there is evidence of significant concerns regarding organ trade or organ allocation. Various studies have clearly shown the workload and emotional stress of intensive-care staff (van Servellen/Leake, 1993; Medland/Ferrans, 1998; Sharp, 1996; Gubernatis et al., 2000). In the study by Gubernatis et al. (2000),

the fear of an additional workload was the most common reason stated by the intensive-care staff for not referring a potential donor. There is hardly any information at the moment concerning institutional motivation; however, Gubernatis et al. showed how much a clear statement by the hospital directors would be appreciated by the employees.

The topic of compensation is often the cause of heated ethical debates. Such compensation is by no means a kind of commission for the doctors in charge of procuring organs. Rather, the intention is to reduce the reservations surrounding organ donation by providing compensation for the additional working time and costs incurred by the hospital. Except in Bavaria, there are currently no provisions for such reimbursement in Germany. In Spain, on the other hand, this kind of compensation has already been provided for some time (see *Section 6.1.1 "The Spanish Model"*).

As already mentioned, both the clear definition of responsibilities and the organisational structure, with competent contact persons who can be reached correspondingly quickly, have a considerable influence. Many improvements in this field were introduced in the context of Germany's Transplantation Act (TPG) which, however, is put into practice very differently in the individual Federal states. Its effects have not yet been systematically studied (and may not yet be detectable due to the brief period of time). In this regard, there is a need for research in Germany. In contrast, other countries, such as Spain, The Netherlands, Great Britain and Canada, have presented data from different hospitals that indicate extremely positive effects (see also *Section 6.1 "The effectiveness of structural improvements"*).

(3) Medical contra-indications

There is no way of preventing the emergence of illnesses in a potential donor that make organ transplantation impossible (this is labelled "morbidity" in the diagram below). The frequency of falsely diagnosed contra-indications, however, is a substantial aspect of the organ donation process than can certainly be influenced, as explained below.

According to a compilation by Wight et al. (2000), the medical contra-indications for organ removal can be divided into absolute contra-indications and those with limited validity. Thus, the absolute contra-indications include active tuberculosis, HIV infection or positive serological results, Creutzfeldt-Jakob disease, septic viraemia, extra-cerebral ma-

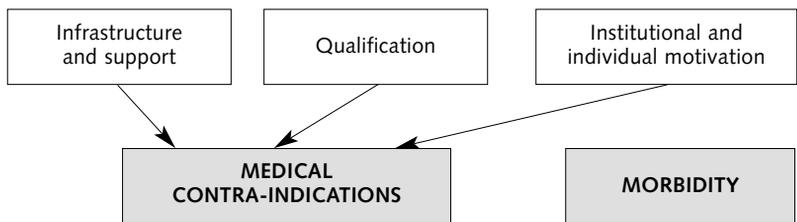


Figure 14: Influencing factors in checking for medical contra-indications

lignant tumour or treatment of such within the past 5 years. In addition to this, there are further diagnoses which only allow the donor's organs to be removed under restricted conditions. Among these are hepatitis C, hepatitis B surface antigen (unless the recipient is also tests positively for hepatitis B surface antigen), agranulocytosis, aplastic anaemia and haemophilia.

Within the framework of the diagnostic phase of the Donor Action programme in two Spanish hospitals, the incorrect diagnosis of medical contra-indications was identified as a reason for the unnecessary loss of organ donors. Following the implementation of special training courses, the number of false contra-indications was reduced to zero (Alonso et al., 1999). One important factor is the professional qualification of the staff and the responsible transplantation officer. Furthermore, the speed with which serological analyses can be performed and professional advice is available is also important. The DSO now offers an extensive range of services in this area, including advisory support, a telephone hotline (24 hours, 7 days a week) and laboratories (Bösebeck/Eisenreich, 2000). Not least, motivational factors at both the individual and the institutional level also certainly play a role again in this phase of the organ donation process (*Figure 14*).

(4) Decision

The most complex pattern of influence within the 6-step donation process is found in the decision for or against donation, i.e. in the conversation with the relatives in accordance with standard practice in Germany and most other European countries (Cohen/Wight, 1999). As explained in *Section 3.2*, two conceivable situations must be considered here:

1. Decision with knowledge of the will of the deceased and
2. Decision without this knowledge.

The earlier chapters of this report already developed detailed models of the influencing factors seen on the part of the relatives and compared them with empirical results. These are to be referred to here. As was seen there, not only the more general values and attitudes of the relatives and/or the deceased have an influence on the outcome of the conversation, but also various other, more or less situation-specific factors.

The conversation with the relatives

The rate of refusal by relatives remains fairly high. Studies from Great Britain and Spain have shown that 24% and 26% of the families refused donation (Stewart et al, 1994; Matesanz/Miranda, 1997). A figure of 73% was even reported in The Netherlands (Kranenburg et al., 1998); the refusal rate in Germany is 37% (DSO, 2000). The great variability of these percentages between the countries allows the assumption that both the method and the point in time of the request for organ donation are of great significance (Cohen/Wight, 1999). The various aspects in this context are examined in more detail below:

- *Decoupling*: There are so far no clear guidelines as to when the option of organ donation should be raised with the relatives. There is empirical evidence that the consent rate



increases when the request for organ donation is not made in the same conversation as the news of the patient's death is broken, but separately, at a somewhat later point in time (so-called "decoupling") (von Pohle 1996; Blok et al., 1999). Cutler et al. (1993) found a significantly higher consent rate in decoupled requests as opposed to simultaneous requests (79% vs. 58%). However, due to the medical demands of organ donation, one cannot wait too long. In practice, one waits for a sign of acceptance of the death of the relative, for example (such as speaking in the past tense).¹

- *Number of people/person making the request:* In an analysis of hospital records over a period of two years (von Pohle, 1996), it was seen that a member of the transplantation organisation not belonging to the hospital staff achieved a considerably higher consent rate among families than did the doctor alone. This may partly be attributable to the fact that the transplantation coordinator used the decoupling method each time, while the doctors only did this in three out of 29 cases. In the study by Cutler et al. (1993), the higher consent rates achieved by the coordinator as compared to the doctor were again mainly attributable to greater use of decoupling.
- *Number of relatives present:* According to experience in Spain, the higher the number of relatives who are to make the decision, the lower the probability of consent becomes, whereas the consent rate was 90% in cases where only a single relative was present.²
- *Attitude, knowledge and self-confidence of the medical personnel:* Siminoff et al. (1995b) found in their previously mentioned study (see Section 4.2) that a positive attitude of the medical professionals towards transplantation medicine was more closely related to successful organ procurement than to their transplantation-specific knowledge (contra-indications and legal basis). However, it should be considered here that, although the authors only surveyed people directly involved with transplantation, the sample also included social workers and clergymen. In 1987, Malecki and Hoffman had already found in a study of 124 nurses that those who felt very uncomfortable about making the request for organ donation only obtained consent from the relatives in 42% of the cases, while nurses who felt more confident achieved an 86% consent rate.
- *Duration of intensive-care treatment:* Further factors also appear to play a role in the decision-making phase. Thus, the rate of consent rises with the number of days the patient spends in the intensive-care unit before dying (0 to 1 day: 57%; 2 to 3 days: 69%; > 4 days: 74%) (Cutler et al., 1993). The authors attribute this to the fact that, the longer the intensive-care treatment lasts, the more the family members begin to accept the patient's critical condition and ultimate death in a kind of process.
- *Conversation:* Based on clinical experience in several European hospitals and a review of the literature, Blok et al. (1999) formulate a few important pillars of the conversa-

1, 2 Personal communication, Dr. B. Miranda, Madrid, 11 July 2000

tion with the relatives: the manner in which the doctors and nurses hold the conversation is very important in ensuring that the relatives understand the concept of brain death. The conversation should be well planned and should take place with the immediate relatives and close friends in a quiet, pleasantly furnished room (see also Gomez-Marinero et al., 1996). The news of death should be broken as early as possible in the conversation; the fears and sadness of the relatives should be empathetically received and discussed. All information should be given to the family clearly and openly. It is important that brain death be understood and accepted as actual death. The family should also continue to be supported during the donation process. They should also be encouraged to see the donor's body frequently in order to counteract fears of mutilation (review in Blok et al., 1999).

In *Section 3.1*, we described models of how the donor's individual decision is made. We also presented models of the development of an attitude among the relatives (*Section 3.2*). It should be recalled that even if the deceased's attitude towards organ donation is known, factors such as experience with the intensive-care staff also play a role.

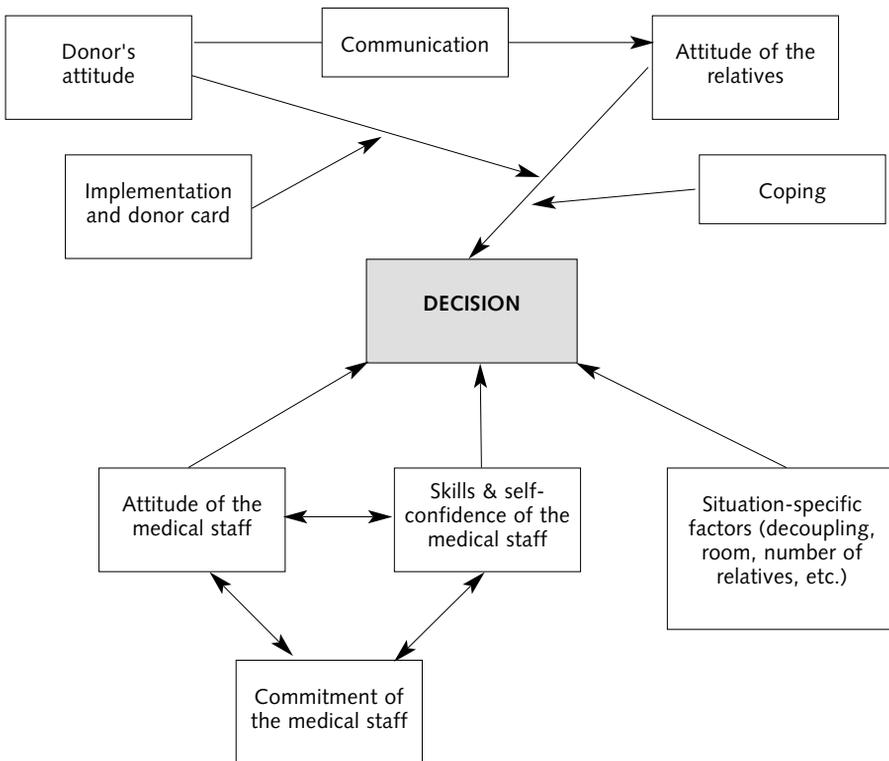


Figure 15: Factors influencing the decision for or against organ donation in the conversation with the relatives

In order to express his or her wishes, the deceased must have signed a donor card (which is partly dependent on the difficulty of such a task in practice, i.e., how easily and where such a card is available) and/or must have spoken to his relatives about the subject. In the latter case, the communication within the family is of decisive significance. As we have seen, even if the deceased's wishes are known, they are not always adhered to. Apparently, further factors also have a bearing here. On the one hand, the relatives' general attitude and their experience during the deceased's intensive care appear to play a role (see also *Section 3.2*). On the other hand, the relatives' ability to cope with the news of the patient's death and the degree to which they are able to make a decision in such a highly stressful situation (the "coping" factor) are also of decisive importance.

In addition to the factors pertaining to the relatives, there are a few influencing variables on the part of the medical staff involved. As shown in the cited studies, the attitude, the commitment, the conversational skills and the self-confidence of the medical staff in such difficult and emotionally stressful tasks are very influential factors. Furthermore, situational factors (the room and the setting for the conversation, the number of relatives present, decoupling of the news of death and the request for organ donation, etc.) also play an important role (see *Figure 15, p. 63*).

(5) Maintenance, (6) Explantation and transplantation

According to the latest DSO statistics, no organ donation occurred in 3.9% of the identified donors in Germany due to failure to maintain homeostasis³ in the brain-dead patient. This figure has thus declined slightly since 1997, when it was 4.8% (DSO, 2000), but some of these cases are unavoidable⁴. On the whole, the role of the maintenance problem need not be given priority with regard to increasing the donation rate. At this stage of the process, the loss is influenced not only by the corresponding hospital's technical capabilities, the staff's professional qualification and the stability of the donor's cardiovascular system, but also by structural and organisational prerequisites (such as how long it takes before an appropriate recipient is found and the organs can be explanted) (*Figure 16*).

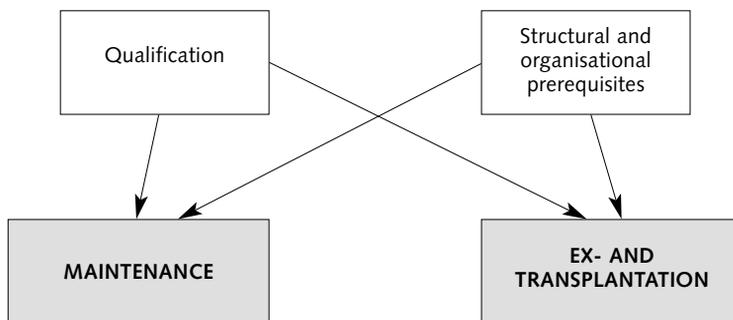


Figure 16: Factors influencing donor maintenance and organ explantation

3 Homeostasis: maintenance of the balance of organ functions.

4 Spain aims to reduce these cases to 2%.



THE "STRATEGY ORCHESTRA"

The long road from the brain death of a potential donor to the removal and transplantation of their organs includes a number of very different factors which are decisively involved in determining whether donation takes place or the potential donor is lost. The complexity becomes evident when the models developed for each step in the previous section are integrated into an overall model (see *Figure 17*). In view of this overall model of the organ donation process, it appears clear that a substantial increase in the organ donation rate cannot be achieved by one single measure.

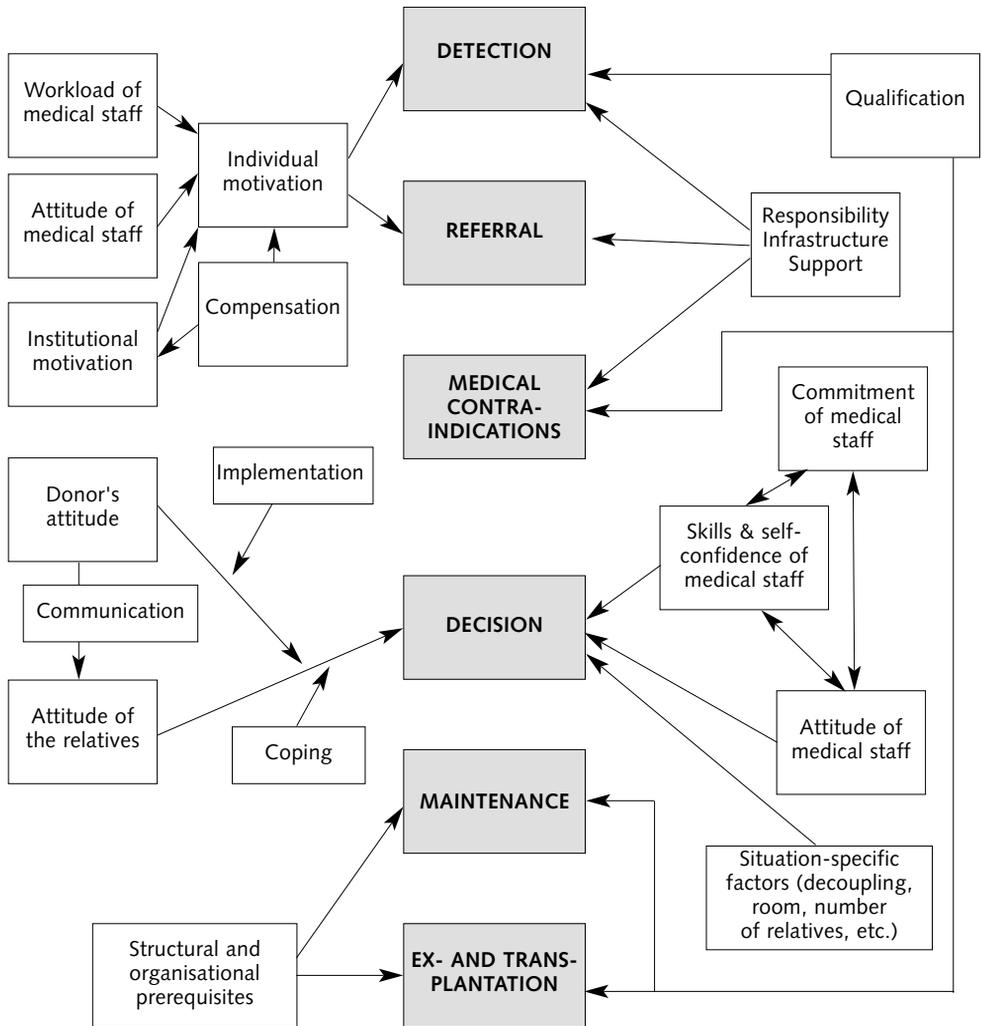


Figure 17: Process model of the overall organ donation process

The influencing factors are of a medical, psychological, structural, technical, individual or institutional, communication-psychological and motivational nature. If a targeted improvement is to be achieved, coordinated measures of equally differing nature must take effect simultaneously at different points of the model: the "strategy orchestra".

Furthermore, the model shows that the result, the organ donation rate, is influenced by the entire process and all its factors. It thus makes little sense to assess the individual measures against this parameter, since no single strategy can be expected to have a linear and directly measurable influence on the organ donation rate. On the other hand, continuous evaluation is important for the legitimation of individual measures. Thus, an appropriate outcome variable must be found for each individual strategy and options considered for valid and reliable measurement. The development of the organ donation rate can then be used as a measure of effectiveness for the entire strategy orchestra, provided that further factors are also monitored, such as the annual number of brain deaths without medical contra-indications (potential donors).

In the following section, a possible strategy orchestra is compiled and approaches for evaluation derived. The points at which an individual strategy will probably show effects are discussed, along with the possible outcome variables.

Step 1a: Systematic analysis of the potential donor pool and determination of the reasons for losses

A baseline evaluation based on the example of the Donor Action programme's diagnostic phase would be useful in order to obtain an exact overview of the potential donor pool (in other words, the number of brain-dead patients without medical contra-indications). This means that experts would have to look through a hospital's medical records, either retrospectively or prospectively, and check every death for organ donation suitability.

In addition to the numbers that could be ascertained concerning donor potential, the reasons for donor loss could also be examined if the procedure followed on the occurrence of brain death were accurately documented. In the ideal case, forms like those in Spain (see excursion in *Section 6.1.1*) could be used. Such a survey is very time-consuming and expensive. Consideration should thus be given to whether this "diagnostic phase" could be performed in model fashion at a few exemplary hospitals. It would then certainly be sensible to use a sample that is as representative as possible of hospitals of varying size and with different facilities.

The benefit of this procedure lies in its precise determination of the primary problems within the 6-step donation process described above. Depending on the results, a series of practical, target-oriented and cause-specific measures could be developed for each hospital. The latest data from the DSO suggest that the primary problem in the donation process

is refusal by the families (DSO, 2000). However, the figures are based not on the total number of potentially suitable donors (such as the analysis suggested here would provide), but rather on the number of donors registered with the DSO.

Step 1b: Attitude, motivation and skills in the hospital

Many structural and organisational improvements, similar to those which have been successfully implemented in Spain and other countries, are also being demanded in Germany by the Transplantation Act and are currently being put into practice by the implementing laws of the individual Federal states (for the example of Bavaria, see Bösebeck/Eisenreich, 2000). This process involves the DSO's regional transplant coordinators and their services (according to Art. 11 TPG), as well as the appointment of so-called transplantation officers, e.g. in Bavaria and Rhineland-Palatinate, in all hospitals with intensive-care beds. This alone could justify the expectation of positive effects.

Baseline analysis

The success of organ procurement depends not only on structural and organisational factors, but also on a number of more psychological and motivational aspects, particularly in the first two steps (within the hospital). In this context, mention should first be made of the individual attitude of the staff and especially the so-called "institutional motivation" for cooperation in the area of organ procurement. Both of these factors would first have to be assessed as a baseline value. Individual attitude and motivation could be determined by way of a scale similar to the "Hospital Attitude Scale" used in the diagnostic phase of the Donor Action programme. An estimation of the hospital management's attitude towards organ donation ("institutional motivation") could be achieved by means of so-called Delphi surveys. Furthermore, the overtime workload of the intensive-care staff should be estimated. With regard to the third step of the organ donation process, an analysis of self-assessed skills relating to the conversation with the relatives would be necessary. Here, questionnaires modelled on the EDHEP programme could be used, although they would have to be modified for prospective surveys. Finally, records concerning the setting of the conversation with the relatives and the reasons for refusal would be very helpful with regard to later measures.

All the above-mentioned baseline analyses, i.e. both the evaluations of the medical records and the baseline values for attitude, knowledge and skills, as well as the records concerning the conversation with the relatives, are to be understood as the basis and starting value for monitoring success. They are thus to be repeated at regular intervals in order to serve as a measure of the success of the various interventions described below.

Step 2a: Measures in the hospital

Furthermore, a modular procedure based on the Donor Action programme should be used in the hospital itself, depending on the results of the diagnostic phase. If the analysis shows that the weak point was primarily found to be inadequate donor detection (e.g. due to incorrectly diagnosed medical contra-indications), detection courses can be implemented. An aspect which is perhaps quite often of influence is the motivation at the individual and institutional levels. As a basic principle, some form of publicity campaign should be run throughout the hospital to promote organ donation. The transplantation officer and the regional DSO coordinator could be responsible for this, as is the case in Spain. The success of such education measures could be gauged via the individual and institutional attitudes. In conjunction with the improvement of the distribution of responsibilities (appointment of a transplantation officer) and the improvement of detection, an increase in the detection rate should eventually set in, compared to the baseline assessment.

In the opinion of many experts, training in holding conversations (such as EDHEP) is generally useful (see Blok et al., 1999). Success measurement has so far only been attempted by way of the assessment of the usefulness for the participants. More "objective" measurement would appear to be very difficult in view of the multitude of factors which influence the decision during the conversation. Quantification via the refusal rate is thus not an adequate solution, since attitude-related factors, the coping mechanisms on the part of the relatives, and perhaps the complex process of development of an attitude in the deceased, have a confounding influence. The use of EDHEP or similar programmes appears to us to be advantageous when the baseline evaluation clearly reveals reservations and uncertainty among the staff, as well as a desire for training. In this case, the effectiveness should continue to be evaluated with reference to the participants' subjective gain.

Step 2b: Public relations

The attainment of a decision in favour of organ transplantation, either by the potential donor while he or she is still alive or by the family following his or her death, requires that measures be undertaken which address not only the hospital setting (i.e. staff training), but also the general public. According to the current state of knowledge, education in the form of information (Where can I get a donor card? What is brain death? How does the allocation system work?) is important for eliminating both concrete and diffuse fears. The stimulation of discussion and exchange within families is also important in ensuring that someone's personal attitude is known to relatives, so that they can make a decision in keeping with his or her wishes in case of death. The problem faced by measures of this kind is that of creating permanent awareness of the subject of organ donation. Positive effects on the level of information among the public were often seen shortly after various campaigns, but without this having any visible effect on the donation rate. However, this is not surprising, considering the number of other factors that also influence the number of organ



donors (see process model, *Figure 17*). Thus, it is again very important monitor success using an appropriate set of instruments and suitable outcome variables. A campaign should then be validated with regard to how strongly it was perceived by the public and whether it was able to communicate transplantation-specific knowledge. If it is specifically geared to the spread of donor cards, for example, its success can be measured by the number of donor card holders determined in surveys. In all evaluations, including those of publicity campaigns, it is important to ascertain a baseline as a reference for change.

In some European countries, such as Spain and The Netherlands, the institutions responsible for organ donation have begun to dispense with large-scale campaigns, or at least limit them, and are instead using continuous press activities (interviews, press releases, etc.) in striving for permanent presence of the topic in the media and public awareness (van Netten, 1999; March/Burgos, 1997).

Possible starting points for future interventions

In accordance with the process model described and the steps derived from it, there are various levels that each require different intervention strategies (see *Figure 18*), where one and the same intervention element can also influence several levels. Thus, for example, broad-based publicity campaigns can equally appeal to potential donors and their families, as well as to the people working in the hospitals. They can thus not only be effective with regard to the person attitude of the individual, and therefore at the decision level, but also influence donor detection on the part of the medical staff.

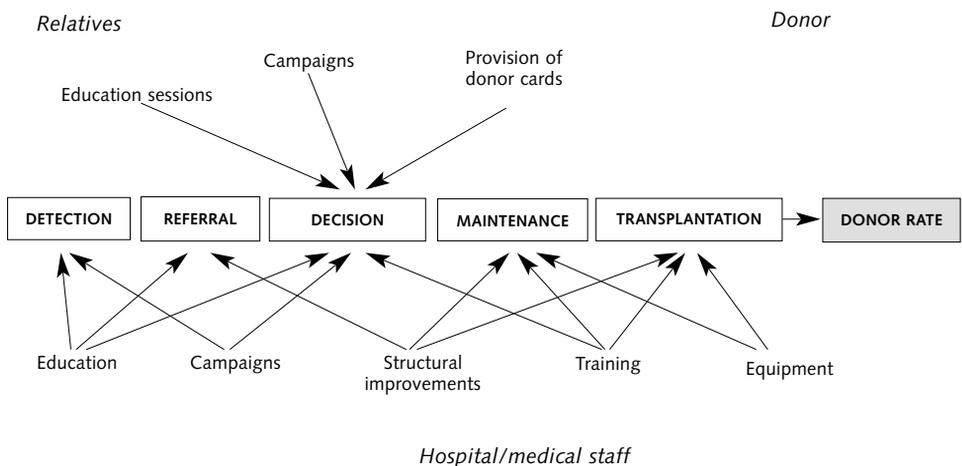


Figure 18: Starting points for various interventions within the donation process

This model of the factors and intervention strategies acting on various levels is to be understood as food for thought regarding a future procedure. It illustrates, on the one hand, that not all strategies can be measured against the donor rate as the sole outcome variable, but rather that sensible outcome variables must be defined for each level, which can serve to measure the success of an intervention. On the other hand, it also becomes evident that different intervention strategies should be implemented at the various levels, in order to achieve a reasonable overall effect, meaning an increase in the donation rate, with the help of such a "strategy orchestra".



APPENDIX



9.1

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9.2 Table of empirical studies

I. Studies on the attitude of the public

Study/Year/ Location	Description	Result
Amir/Haskell (1997) Israel	Sample: N = 139 students Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive and quantitative (donors vs. non-donors) Outcome variable: Attitude, anxiety	Differences examined between potential donors and non-donors. According to the results, the absence of a donor card is not to be understood as a rejection of donation, but more determined by ambivalent feelings of fear and avoidance.
Cheung et al. (1998) USA	Sample: N = 421 Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive + quantitative Outcome variable: Attitude, donor card	Comparison of persons of Asian descent with white residents. The former have a more negative attitude and less frequently a donor card. They feel less obliged to the community, are more concerned about the integrity of the body following death and have less trust in the doctors.
Davidson/Devney (1991) USA	Sample: N = 187 Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive, correlative Outcome variable: Attitude regarding blood, bone marrow and organ donation	African-Americans have a negative attitude towards donation; mistrust of the medical profession is the strongest influencing factor.
Dominguez et al. (1991) Puerto Rico	Sample: N = 500 Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive + quantitative Outcome variable: Awareness, attitude	Gender, religion, income or acquaintance with a dialysis patient had no influence on attitude. On the other hand, high age (!!) and acquaintance with a transplant patient were connected positively with attitude.

Study/Year/ Location	Description	Result
Forsa Survey (1999) Germany	Sample: N = 1,003 (systematic random sample) Type of study: Survey Design: One-point Survey instrument: Telephone interviews Evaluation strategy: Descriptive Outcome variable: Attitude	Two-thirds have concerned themselves little or not at all with organ donation (more frequently women, educated persons). Passive acceptance: 78%; active acceptance: 63%. 41% believe they know where donor cards are available. 11% possess a donor card. Occupation with the topic is a significant influencing variable.
Gallup poll 1993 USA	Sample: N = 6,127 Type of study: Survey Design: One-point Survey instrument: Telephone interview Evaluation strategy: Descriptive Outcome variable: Attitude	85% general acceptance. 25% exclude own donation (of these, however, only half can give reasons). 80% would accept an organ.
Martinez et al. (1991) Chile	Sample: N = 421 Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive Outcome variable: Attitude	Willingness to donate own organs: 80%; lower for organs of relatives (64%).
Pike et al. (1992) South Africa	Sample: N = 2,750 Type of study: Survey by a market research institute Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive Outcome variable: Attitude	80 to 90% advocate organ donation in various social strata. Willingness to donate was lower in urban regions than in rural areas.
Rene et al. (1995) Puerto Rico	Sample: N = 158 (53 hospital employees and 105 patients) Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive Outcome variable: Attitude towards various aspects of transplantation	On the whole, relatively low level of information. 85% would donate to own family members.

Study/Year/ Location	Description	Result
Roels et al. (1997) Belgium	Sample: N = 1,306 from 3 generations Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive Outcome variable: Knowledge, attitude	Awareness relatively good, but level of information criticised as being too low. Acceptance rate high, but declines with age. The majority of the respondents said they were in favour of self-determination regarding organ donation.
Schütt/Schroeder (1993) Germany	Sample: 105 schoolchildren, 53 doctors, 130 nurses, 119 non-medical employees Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive Outcome variable: Attitude	100% would accept a transplant organ and all indicated a willingness to donate after death. Living donation was generally rejected by 30 to 40%
Schutte/Kappel (1997) USA	Sample: N = 54 Type of study: Group discussions Design: One-point Survey instrument: Conversation (non-standardised) Evaluation strategy: Descriptive Outcome variable: Attitude + beliefs	Poor level of information regarding distribution of organs. Often mistrust concerning allocation (primarily among black citizens). Incentives were rejected.

II. Studies on the attitude of medical professionals

Study/Year/ Location	Description	Result
Bunzel/Smeritschnig (1999) Austria	Sample: 290 medical students Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: - Outcome variable: Interest, attitude, knowledge	Interest very high. If knowledge of the legal basis, then fewer reservations; on the whole, however, strong reservations. Most likely to donate heart (!!). Note: Replication of the studies by Streng.
Gaber et al. (1990) USA	Sample: 765 non-doctor HCPs (primarily nurses) Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Quantitative (chi-square) Outcome variable: Attitude, knowledge	High acceptance (90%), low willingness to donate (45%, i.e. less than in the general public). 35% had a donor card. Only 65% considered brain death to be actual death. High degree of uncertainty concerning the request for donation. Effectiveness of programmes: increased knowledge of legal aspects, increased willingness to donate and to request donation.

Study/Year/Location	Description	Result
Laederach-Hoffmann/Isenschmid-Gerster (1998) Switzerland	Sample: 117 medical students Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Descriptive + quantitative (correlation, chi-square, U-test) Outcome variable: Interest, attitude, knowledge	Strong interest, moderate knowledge of legal regulation. Approx. 50% had fundamental reservations (the better informed they were, the fewer reservations they had). Also, sequence of the organs (most likely to donate: kidney). Note: Replication of the studies by Streng.
Minz et al. (1998) India	Sample: 204 doctors and nurses (+ "others") Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Quantitative (chi-square) Outcome variable: Attitude	High level of information (80 to 97%), high acceptance (74%), great fear of organ trade (94%), 50% in favour of financial support for donor families.
Prottas/Levine Batten (1988) USA	Sample: N = 2,323 (246 neurosurgeons, 222 administrative employees, 227 nursing directors, 878 intensive-care nurses, 750 "public sample") Type of study: Survey Design: - Survey instrument: Questionnaire or telephone interview (public sample) Evaluation strategy: Descriptive + multivariate Outcome variable: Attitude	Generally strong acceptance (>90% in all groups). Passive acceptance among medical staff also >90%, in the general public 72%. Doctors show strong feelings of discomfort with respect to dealing with the donors' families. The attitude of a ward's senior physician had a clear influence on the attitude of his staff.
Schweidtmann/Muthny (1997) Germany	Sample: 134 doctors Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: - Outcome variable: -	Greatest support for informed consent. Generally high acceptance of transplantation (93%). 96% accept brain death. 96% find dealing with relatives stressful. 98% consider training to be important.
Siminoff et al. (1995b) USA	Sample: 1,797 HCPs (doctors, nurses, social workers/clergymen) Type of study: - Design: - Survey instrument: Review of the medical records + HCP interviews Evaluation strategy: Quantitative (primarily correlation & chi-square) Outcome variable: Attitude, knowledge, behaviour (approach, procurement)	Knowledge: Specific knowledge of criteria (e.g. metastasising cancer) low, but still high hit ratio regarding patient suitability (approx. 75%). HCPs who correctly identified patients approached families more frequently and achieved higher procurement. Attitude: 50% possessed a donor card. The more positive the attitude, the greater the chance of a conversation and also of success. HCPs do not feel competent with regard to the request. Programmes should concentrate on attitudes. Note: Very meticulous study.

Study/Year/ Location	Description	Result
Sque et al. (2000) Great Britain	Sample: N = 2,465 nurses Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Quantitative (factor analysis) Outcome variable: Attitude, knowledge	Generally high acceptance (78%); however, various fears in addition to positive, altruistic attitudes.
Streng (1996) Germany	Sample: 83 medical students Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Very descriptive! + quantitative (chi-square) Outcome variable: Interest, attitude, knowledge	Great interest. High general acceptance, but only 50% personally. Only 4% donor card. More than half stated spontaneous reservations. Donation of kidneys most likely. Note: Extensive discussions (including ethical/philosophical aspects).
Streng (1998) Germany	Sample: 125 medical students (73 in first semester, 52 in practical training year) Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Descriptive + quantitative (contingency tables) Outcome variable: -	Willingness to donate and percentage with donor card higher in comparison with first study. Confrontation with dying patients had positive influence. Equal degree of reservations in both groups. Concept of brain death predominantly rated as worthy of discussion. This acceptance had a great influence on attitude. Clinicians talked about the topic with others more frequently. Students at the beginning of their studies hoped their course would help them reach a decision (however, only 27% of those in practical training year had a positive attitude). Note: Follow-up study to Streng (1996)
Weber (in print) Germany	Sample: n = 759 doctors (1994/5), n = 500 doctors (1999) Type of study: Survey Design: Two point Survey instrument: Questionnaire Evaluation strategy: Quantitative Outcome variable: Attitude	High acceptance (approx. 90%). However, active acceptance slightly regressive in the observation period.
Weber/Canbay (1999) Germany	Sample: 759 doctors, 820 nursing staff Type of study: Survey Design: - Survey instrument: Questionnaire Evaluation strategy: Quantitative (Mann-Whitney U-test) Outcome variable: Attitude	Generally positive attitude. Doctors: women had donor card more often than men, younger people more often than older people; willingness greater than in general public, but also more reservations. Note: Response rate 50% and 25%, respectively.

Study/Year/ Location	Description	Result
Wight et al. (1998) Multi-centre (Spain, Netherlands, Great Britain, Canada)	Sample: Not stated Type of study: Survey Design: One-point Survey instrument: Questionnaire Evaluation strategy: Descriptive + quantitative Outcome variable: Attitude	Active acceptance in 79%. Low rating of own skills regarding brain death criteria (44%) and conversation with relatives (31%). Differences in inter- national comparison.

III. Studies on strategies geared to the general public

IIIa. Mass campaigns

Study/Year/ Location	Description	Result
Callender et al. (1997) USA	Sample: Not stated Design: Post Type of intervention: Mass media campaign, lectures, etc. (not described more specifically). Focused on the black minority Evaluation strategy: Descriptive Outcome variable: Various meas- ures (donor card holders, atten- dance at lectures, etc.)	Various indications of a successful campaign.
Gäbel/Rehnquist (1997) Sweden	Sample: Info brochure to 4.2 mil- lion households, evaluative Sur- vey of 1,000 persons Design: Pre and post Type of intervention: Brochure, advertisements in newspapers, info material in chemists and hos- pitals Evaluation strategy: Descriptive Outcome variable: Response to the campaign, entry in registry	Prior to the campaign 79% had a positive attitude. 80% of the respon- dents had read the brochure, 65% had spoken about it with relatives or colleagues. In the 9 months following the two-day campaign, 15% of the population registered themselves for the first time (48% "yes", 52% "no" to organ donation).
Jacob et al. (1996) France	Sample: N = 500 Design: Post Type of intervention: Posters, TV & radio spots, advertisements Evaluation strategy: Descriptive Outcome variable: Response to the campaign	46.9% had heard of the campaign, of whom 62.5% had discussed the sub- ject with their relatives. On the whole, the majority felt poorly informed on the subject (63%) and would have liked a national information campaign (92%).

Study/Year/ Location	Description	Result
<p>Persijn/Van Netten (1997)</p> <p>Netherlands</p>	<p>Sample: 1988: N = 1,077 1990: N = 1,637 1994: N = 1,108</p> <p>Design: -</p> <p>Type of intervention: Telephone hotline, distribution of information material and donor cards, public campaigns, teaching material for schools, National Donor Week, exhibition</p> <p>Evaluation strategy: Descriptive</p> <p>Outcome variable: Participation, donor card holders</p>	<p>Significant increase of activities in all areas from 1991 to 1996. Increase in donor card holders since 1990 (21% have a card, 19% have a positive attitude towards them, but no card yet; 32% are uncertain, with fear playing a role, 16% reject organ donation). Despite all this, however, no increase in the donation rate.</p>
<p>Sanner et al. (1995)</p> <p>Sweden</p>	<p>Sample: N = 5,600 (random samples in campaign areas and control groups)</p> <p>Design: Pre-post, control groups</p> <p>Type of intervention: Information campaign.</p> <p>A: Extensive info package B: Brochure in homes C: Both</p> <p>Evaluation strategy: Descriptive plus chi-square</p> <p>Outcome variable: Attitude, knowledge, donor card</p>	<p>No attitude changes (!!). Brochure most effective (number of donor cards more than double). Newspaper ads given most attention, posters and TV spots least. Influencing factors: age and education. Belief in God and afterlife has a negative influence. People are more willing to donate than to consent to removal of relatives' organs. A maximum of 75% of the potential donors could be recruited with public campaigns (= number of people with a positive attitude). Attitude change is necessary for a further increase (i.e. personal address, long-term programmes).</p> <p>Note:</p> <ul style="list-style-type: none"> - Very extensive, careful study - Interesting social-psychology approaches - Important to make it easy for the people to implement their decision (i.e. by mailing donor cards).
<p>Van Netten (1999; 2000)</p> <p>Netherlands</p>	<p>Sample: 12.2 million residents over 18 years of age (campaign), survey of a random sample pre and post</p> <p>Design: Pre-post</p> <p>Type of intervention: Two-pronged information strategy (neutral vs. soft selling)</p> <p>Evaluation strategy: Descriptive</p> <p>Outcome variable: Entry in a register, awareness of the topic</p>	<p>84% of the target group reached. Degree of familiarity with organ donation law increased by 21%. Positive attitude declined from 93% to 84%. 36% of the persons sent mail registered themselves. Two-pronged strategy proved not to be useful.</p>

Study/Year/ Location	Description	Result
Wolf et al. (1997) USA	Sample: Not stated Design: Post Type of intervention: (Mass-media) Campaign (Save your life ... Share your decision) Evaluation strategy: Descriptive Outcome variable: Response to campaign	59% remembered the campaign, 10% of these signed a donor card as a result. On the whole, 40% stated they had decided in favour of organ donation.

IIIb. Lectures and instruction

Study/Year/ Location	Description	Result
Harms et al. (1997) USA	Sample: N = 354 Type of study: Survey Design: Pre-post (retrospective) Type of intervention: Public information event on the subject Evaluation strategy: Descriptive Outcome variable: Attitude, intention to act	Survey of visitors with a simple 4-item questionnaire. Willingness to donate organs appears to rise (66% of those who did not want to donate prior to the presentation had changed their attitude. However, all questions were posed following the lecture). Also: the outcome was again only the indicated willingness to register, to speak with relatives or to sign a donor card.
Meier et al. (2000) Germany	Sample: N = 67 (Experimental Group N = 31, Control Group N = 36) Type of study: Quasi-experimental Design: Pre-post, control groups Type of intervention: Educational segment Evaluation strategy: Quantitative Outcome variable: Knowledge, fears, willingness to donate	Knowledge and willingness to donate increased, fears decreased. Good acceptance of the programme. Note: One of the few controlled studies.
Thompson et al. (1993, 1997) Australia	Sample: 600 Australian secondary schools Type of study: - Design: Pre-post (retrospective) Type of intervention: Educational segment Evaluation strategy: Descriptive Outcome variable: Attitude, involvement with the topic	Programme was well received. Attitude improved. According to their own statements, the schoolchildren also discussed the topic outside the classroom.

Study/Year/ Location	Description	Result
Weaver et al. (1999) USA	<p>Sample: N = 216 (6 classes of 36 school children each)</p> <p>Type of study: Semi-experimental</p> <p>Design: Pre-post, control groups</p> <p>Type of intervention: Educational segment</p> <p>Evaluation strategy: Quantitative</p> <p>Outcome variable: Knowledge, attitude</p>	Knowledge increased, attitude was positively changed.
Zambudio et al. (1998) Spain	<p>Sample: N = 428 schoolchildren (8 to 12 years old)</p> <p>Type of study: -</p> <p>Design: 3-point, one-group</p> <p>Type of intervention: Educational segment</p> <p>Evaluation strategy: Quantitative</p> <p>Outcome variable: -</p>	Knowledge increased significantly

V. Studies on strategies geared to the hospital setting

IVa. Effectiveness of structural improvements

Study/Year/ Location	Description	Result
Alonso et al. (1999) Spain	<p>Sample: Two hospitals</p> <p>Type of study: -</p> <p>Design: Two-point</p> <p>Type of intervention: Donor Action (see <i>Section 6.1</i>)</p> <p>Evaluation strategy: Descriptive, pre-post</p> <p>Outcome variable: Attitude of the staff, procurement rate</p>	<p>Main problems: low participation of the medical staff in the organ donation process, low identification of donors, high rejection rate by families, hospital-internal organisational problems. Detection rate increased (from 81% to 98%). No loss of donors due to organisational problems or incorrect medical contra-indications. Rejection by the families dropped. Staff's skills and involvement rose. Number of donors rose (from 32% to 44% of the potential donors).</p> <p>Note: Brief review of a relatively extensive and successful programme. International project (Donor Action).</p>

Study/Year/ Location	Description	Result
Dawidson et al. (1993) USA	Sample: One large hospital Type of study: - Design: Multi-point Type of intervention: "Aggressive" procurement strategy Evaluation strategy: Descriptive Outcome variable: Donation rate	A clearly rising donation rate in contrast to the national trend. Note: Very brief
Gubernatis et al. (1997) Gubernatis (1999) Germany	Sample: 125 hospitals Type of study: - Design: Multi-point Type of intervention: Establishment of a service centre (telephone advice; coordination, organisation; advice on medical problems; laboratory analyses; brain death diagnosis) Evaluation strategy: Descriptive Outcome variable: Donor referrals, donation rate, time from consent to explantation	Increase in the donation rate, especially in smaller hospitals.
Matesanz et al. (1996a) Spain	Sample: Nationwide study Type of study: - Design: Multi-point Type of intervention: Donor Action (see Section 6.1) Evaluation strategy: Descriptive, pre-post Outcome variable: Donation rate, referral rate	Small hospitals profit from the ONT's service and increase their percentage of the number of donors achieved.
Shafer et al. (1997) USA	Sample: 29 hospitals Type of study: - Design: - Type of intervention: Creation of a coordination centre Evaluation strategy: Descriptive, pre-post Outcome variable: Donation enquiries, donations, consent rate	Enquiries, donations and consent rate increased considerably (80 to 313%).
Trafford et al. (1997) Great Britain	Sample: Three hospitals Type of study: - Design: Two-point Type of intervention: Donor Action (see Section 6.1) Evaluation strategy: Descriptive, pre-post Outcome variable: Donation rate	122% increase in the donation rate after 6 months, compared to the same period of the previous year.



Study/Year/ Location	Description	Result
Wight et al. (2000) Spain	<p>Sample: Two hospitals</p> <p>Type of study: -</p> <p>Design: Multi-point</p> <p>Type of intervention: Donor Action (see <i>Section 6.1</i>)</p> <p>Evaluation strategy: Descriptive, pre-post</p> <p>Outcome variable: Donation and detection rate</p>	<p>Results of Alonso et al. also confirmed after three years.</p> <p>Note: Follow-up study to Alonso et al. (1999).</p>

IVb. Effectiveness of personnel training measures

Study/Year/ Location	Description	Result
Muthny et al. (1995) Germany	<p>Sample: 184 doctors</p> <p>Type of study: Survey following an intervention</p> <p>Design: Retrospective, one-point</p> <p>Type of intervention: EDHEP</p> <p>Evaluation strategy: Descriptive</p> <p>Outcome variable: Satisfaction with the workshops, expected skills</p>	<p>Overall rating very positive (92%). Desire for refresher courses (70%). The large majority of the participants expects better skills, one-third expects a higher consent rate.</p>
Muthny (1997) Germany	<p>Sample: 184 doctors</p> <p>Type of study: Survey following an intervention</p> <p>Design: Retrospective, one-point</p> <p>Type of intervention: EDHEP</p> <p>Evaluation strategy: Descriptive + quantitative, group comparison (ANOVA)</p> <p>Outcome variable: Satisfaction with the workshops, expected skills</p>	<p>–</p> <p>Note: Virtually the same study as that of Muthny et al. (1995)</p>
Neel et al. (1991) USA	<p>Sample: Not stated</p> <p>Type of study: -</p> <p>Design: -</p> <p>Type of intervention: Use of an "altruistic marketing strategy" in hospital staff (no further details)</p> <p>Evaluation strategy: Descriptive</p> <p>Outcome variable: Actual donation rate in California</p>	<p>In the course of three years, the actual donation rate rose from 24.5 pmp to 32.6 pmp, indicating that the maximum number of potential donors (40 pmp) was approached.</p>

Study/Year/ Location	Description	Result
Riker/Wight (1995) USA	Sample: 155 doctors (trained vs. untrained) Type of study: Survey Design: Two-point Type of intervention: Two-hour lecture on organ transplantation Evaluation strategy: Descriptive Outcome variable: -	Significant increase in conversations with the families (from 1% to 68%) and in the consent rate (from 0% to 32%) among the trained doctors as compared to the untrained doctors in the same hospital. However, the very low baseline rate must be considered here. The effects had disappeared again after 6 months.
Robertson et al. (1998) USA	Sample: 136 hospitals (22 with programme, 114 without) Type of study: Analysis of the donation data Design: Two-point <i>Type of intervention:</i> Courses on the implementation of new legal and organisational regulations Evaluation strategy: Descriptive Outcome variable: Referral of medically suitable donors	Significantly lower growth in the number of detected and actual donors in untrained hospitals.
Singer/Rachmani (1997) Israel	Sample: 204 doctors and nurses Type of study: Survey following an intervention Design: Two-point Type of intervention: EDHEP Evaluation strategy: Descriptive + quantitative Outcome variable: Satisfaction, knowledge, donation rate	Significant increase in knowledge. Subjectively increased security in conversation with the relatives. Even more positive attitude towards organ donation. Donation rate and refusal rate unchanged, however.
van Dahlen et al. (1996) van Dahlen et al. (1999) Netherlands	Sample: 430 doctors and nurses Type of study: Survey following an intervention Design: Retrospective, one-point Type of intervention: EDHEP Evaluation strategy: Descriptive Outcome variable: Satisfaction with the workshops, expected skills	Subjectively high learning effect. Lower "barriers" surrounding the request for organ donation. Feedback from the moderators, role-playing and video demonstrations were the most helpful.
Wight et al. (2000) Spain	Sample: Participants from two Spanish hospitals Type of study: Survey following an intervention Design: Retrospective, one-point Type of intervention: EDHEP Evaluation strategy: Descriptive Outcome variable: Expected skills	Higher self-assessment in relation to various transplantation-specific tasks (consolation, notifying the coordinator, explaining brain death criteria, requesting organ donation).

9.3 Summary of the results of an expert discussion

In the framework of a workshop held by the BZgA on 27 March 2001, the authors of this report had the opportunity to present their research work. The goal of this workshop was to discuss the study results within a panel of experts and jointly determine the need for further research.

The most important results of this discussion, with regard not only to the need for further research, but also to concrete approaches for strategies and measures for improving the organ donation situation in Germany, are presented in the following brief summary.

Need for further research

The expert discussion clearly revealed a still considerable need for research concerning various aspects of organ donation. This need for research arises not only from questions which have so far remained unanswered, but also from methodological difficulties and inadequacies of a number of studies. The few studies available for Germany each reflect only a small segment and occasionally display major methodological deficiencies.

The need for continuing studies and research, as determined in this discussion, predominantly covers the following aspects:

- Need for empirical research concerning the donor potential,
- Need for knowledge concerning behaviour predictors,
- Need for knowledge concerning the effectiveness of staff training,
- Need for research on the effectiveness of mass communication measures.

Need for empirical research concerning the donor potential

In the studies examined, there are some major differences in the data concerning the donor potential and the organ donations actually realised (cf. *Section 2.1*) – in both international comparisons and comparisons of the individual Federal states. The causes of these differences were found to be, on the one hand, considerable methodological differences in study design and, on the other hand, fundamental methodological difficulties of retrospective studies on the organ donation potential. Since, for example, the documentation conditions in German hospitals make it nearly impossible to learn anything about the organ donation potential a year later, such a study must take place soon after the event. To be useful, the cases should thus be evaluated within a week of death or closing of the medical records. In addition, hardly any differentiated information is available on many data items. The available studies do not, for instance, indicate the nature of the medical contra-indications documented, whether they increased, or how the detection rate was determined.

The data basis in Germany is generally inadequate – partly due to the fundamental difficulties of retrospective studies on the donor potential, partly because of organisational situations in the hospitals – and insufficient for determining clearly prioritised action. Among the reasons for the hitherto insufficient data basis are the very different attitudes of the hospitals with regard to transparency in the field of organ donation: while some find transparency important and necessary in precisely this area, other hospitals reject such a request, considering it interference in internal affairs.

More comprehensive findings are promised by a representative study planned by the DSO, in which all deaths in intensive-care units in the three states of Bavaria, Hesse and Saxony-Anhalt are to be evaluated over a period of one year. This study is intended not only to provide more exact findings on the available donor potential in Germany, but also to give insight into the obstacles within the organ donation process that prevent organ donation.

Need for knowledge concerning behaviour predictors

Against the backdrop of the studies evaluated that deal with issues and models of the individual decision (cf. *Section 3.1*), and the finding that the large majority of the population advocates organ donation in general, but that this positive attitude is only documented to a small degree, considerations concerning the link between attitude and behaviour encompassed a large portion of the discussion.

The great discrepancy between attitude and behaviour, evident both from the studies and from practical experience, was assessed as being a generally recognised phenomenon which can also be seen to a similar extent in other social areas. For this reason, among others, it was decided that the significance of attitude with regard to actual behaviour, and the value of its determinative quality, is rated too highly. Attitude cannot be considered the only determinant for behaviour, and a forecast of behaviour requires a number of additional predictors. Further research is necessary in this area, in order to determine a more reliable method of predicting behaviour with regard to organ donation. Only then can the question be posed as to how a change in behaviour to reflect attitude can be achieved or promoted.

Need for research on the effectiveness of mass communication measures

Mass communication measures packaged in campaigns are also an important means of delivering information to a broad public, communicating facts and generating a general climate in the field of organ transplantation. Based on scientific findings, they should deliver previously determined, clear messages that are suitably prepared for the individual media and target groups. Against the backdrop of a single controlled study in this field (cf. *Section 5.1*), the discussion primarily focused on the conclusion also drawn by the authors of the study: a mass-media campaign only achieves relatively limited effects. This interpretation was contradicted in the discussion, since neither background information nor the conditions of the campaign were presented in the study. Statements concerning the effectiveness and benefits of a campaign should and can, however, only be made on the basis of differentiated consideration of not only the background and conditions of a given cam-



paigned – such as scope, duration and acceptance of individual elements – but also the individual campaign elements.

The conclusion, commonly drawn prematurely, that campaigns are possibly only perceived to a low degree, and the existence of only one controlled study, make it clear that a need for further research exists, particularly with regard to the effectiveness of mass communication measures.

Need for knowledge concerning the effectiveness of staff training

Given the importance of the conversation with the relatives for the decision-making process regarding organ donation, and the significant personal strain on doctors and nursing staff associated with the situation, training measures primarily concerning the method of dealing with mourning processes are both desirable and necessary for medical staff.

Against this backdrop, EDHEP training, which is currently the most widely implemented method, was generally recognised as being important and necessary, even though systematic research on this programme is still lacking. The problematic aspect noted in the report, i.e. that the evaluation of EDHEP seminars has so far been based solely on self-assessments by the participants directly after the training sessions, was confirmed as being a weak point during the discussion. With regard to the actual effects, more precise findings should be procured with the help of longitudinal studies. For example, repeat surveys of the seminar participants at a later point in time would be desirable and possibly also practicable, e.g. via the hospital coordinators.

Approaches for further measures

The donor potential in Germany is greater than the current number of donations actually realised nationwide. This leads to an important approach for future activities, which is simultaneously linked to the important question as to how a change in behaviour to reflect attitude can be achieved or promoted.

With regard to the various target groups for education measures – general public, medical staff, hospitals (and their financing organisations) – various content focuses for future interventions crystallised during the discussion, where it should not be overlooked that each of these target groups has a common overlapping group. That is, anyone can assume any possible role within the organ donation process, be it that of a potential donor or relative of a deceased person, or that of someone who is professionally involved with organ donation in their capacity as a doctor or nurse.

Focus: Content of education measures

The fundamental content and goals of education campaigns should continue to be concerned with the task of maintaining awareness of the subject of organ donation and moti-

vating people into making a decision and a clear statement of intent (written or oral) during their lifetime. In order to strengthen the reputation and acceptance of organ donation both in society and in hospitals while creating a fundamentally more positive climate, the significance and role of organ donation as a component and necessary prerequisite of transplantation medicine should also be communicated more clearly.

In view of the discrepancy between the very common positive attitude towards organ donation and the still relatively low number of donor card holders, measures should increasingly focus on the signing of donor cards and also on encouraging discussion on the subject of organ donation and personal attitudes towards it in the family setting. In this respect, the donor card, in addition to its function as a document, can also assume the role of a multiplier in that filling it out triggers discussions among relatives and friends.

Increased publicity for the donor card requires that it be correspondingly available and easy to obtain. The current distribution system should be examined and options for its optimisation considered.

Focus: The hospital as an intervention site

Not only structural and organisational features within the organ donation process, but also the skills and motivation of the medical staff play a decisive role in the realisation of organ donations. Accordingly, both areas offer very important starting points on which measures for optimising the organ donation process should concentrate. Furthermore, it is also important, particularly in smaller hospitals, to create a fundamental awareness of organ donation, emphasise its significance as a community task and give it a more positive image, so that it is considered as a possibility in the first place.

Comprehensive structural improvement programmes that target hospitals with high case numbers, such as Donor Action, can only be sensibly implemented in part in view of the specific situation in Germany. As opposed to this, approaches appear more promising which define and organise the accompaniment of the process surrounding organ donation as a service for hospitals and contribute to the professionalisation of the process through a division of labour and corresponding quality management.

Training measures for doctors and nursing staff should primarily target communication with the mourning relatives. The focus here should be on sensitisation concerning the topics of death and mourning, as well as the perception of, and coping with, mourning processes. Above all, specific involvement with the topic, reflection on personal experiences and concrete exercises should enable the staff to interact appropriately with the mourning relatives and give them the secure feeling of being able to recognise the right moment to request an organ donation.

Conclusion

As a comprehensive review, compilation and analysis of the current state of research concerning the various aspects of the organ donation process, the expert report was rated as being a pioneering research paper for future strategies and measures. As was confirmed by the panel of experts, the report offers a number of possible and necessary approaches and impulses for further measures for improving the organ donation process, of which some were already able to be addressed in detail and substantiated within the framework of the discussion. In view of the abundance and diversity of the aspects introduced and discussed, the next step should be to carefully examine and systematise the results of both the report and the discussion. The goal is a coordinated approach based on the division of labour between all the participants - including the health insurance funds, the Federal states, the German Transplant Society, the German Hospital Federation and patients' associations.

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