

Traumatic Memories of Relatives Regarding Brain Death, Request for Organ Donation and Interactions with Professionals in the ICU

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Little is known about the memories of relatives after they have been confronted with the brain death of a loved one and the request for organ donation. We conducted this study, guided by Grounded Theory, to explore relatives' experiences, their interactions with health care providers and what influenced their memories. We interviewed 40 relatives (31 consenting to and 9 refusing organ donation) of 33 brain-dead individuals. Relatives described their experiences as a difficult process composed of several stages spanning from the initial encounter to the final decision about donation. Long-term memories of bereaved relatives were influenced by the characteristics of their decision-making style (clear vs. ambivalent) and the perceived quality of the interaction with professionals on the intensive care unit. Organ-focused behavior of professionals and an ambivalent decision-making style of relatives appear to be risk factors for traumatic memories.

Key words: Brain death, interaction of professionals with relatives, organ donation

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Introduction

To judge by the volume of published research, the psychosocial well being of living organ donors after the donation has been much more widely addressed than the welfare of relatives who must decide upon organ donation on behalf of a brain-dead family member. The aim of this study was to gain insight into the experiences of such relatives by exploring memories of their experiences. The primary focus was upon recollection of interactions with health-care providers during the period surrounding the decision of organ donation of their deceased loved ones, as well as the impact this life event had on their mental health 6 months to 1 year after the organ request. Qualitative research is the appropriate scientific method to explore such

issues and to generate hypotheses for which quantitative methods can subsequently be applied.

The literature on organ procurement identifies two main obstacles in the procurement process: lack of timely identification of potential donors by intensive care (IC) health-care providers, and the attitudes of relatives of brain-dead individuals who refuse organ donation (1–7). Relatives have been studied in relationship to circumstances that may enhance their acceptance of organ donation (5,8–10), the stability of their decision (11), the impact of the decision 6 months after donation (12) and families' emotional characteristics and coping strategies (13).

The narrow focus of the literature on increasing organ donation is understandable, given the urgency prompted by rapidly growing waiting lists of eligible organ recipients, and the suffering and dying of patients on these lists. The focus of our study was primarily the experiences of relatives of brain-dead patients, with a particular emphasis upon identifying those influences that were perceived to have been helpful or traumatic. A better understanding of the experiences of such individuals may serve to improve the awareness among IC providers that relatives of brain-dead patients are people with needs of their own, particularly during such an extremely stressful event in their lives. An appreciation of the relatives' situation may also aid in preventing providers from interacting with them solely as people who can make organ donations possible (14).

The Swiss context

Switzerland is a country situated in the center of Europe, with 7.3 million inhabitants who speak German, French or Italian as national language. In 2005 the donation rate was 12.2 brain-dead donors per million inhabitants. Donation rates, however, vary considerably among the language groups: in the German part 11 per million; in the French part 13 and in the Italian part, 28 (15).

A national Swiss transplantation law is still pending. There is no Central Registry in which citizens can register their wishes concerning organ donation. Relatives of potential brain-dead donors are explicitly asked for organ donation, and close relatives have the first right to consent or not to consent. Three months after donation, a letter is sent by the transplant coordinator to thank the relatives for

donation and to inform them which organs have been successfully transplanted. No formal procedure for follow-up contact with donor families or bereavement counseling exists.

Methods

This study is the qualitative component of a Swiss multicenter study exploring experiences of relatives related to an organ-donation request. Six months after the organ request relatives are contacted by phone by the local transplant coordinator or an intensive care unit (ICU) professional. They are asked how they are doing and if they are willing to fill out a questionnaire about their experiences in the ICU. On the questionnaire, relatives are also asked if they are willing to be personally interviewed. Results of the questionnaire survey will be reported elsewhere.

Relatives from 37 brain-dead patients volunteered and consented to be interviewed for the qualitative study. We expanded recruitment by purposely including people from three situations not represented in the original sample, namely, two parents who had lost a small child and one person whose relative had died after a long illness. The characteristics of the relatives ($n = 40$) and their brain-dead loved ones ($n = 33$) are shown in Table 1. Interviews took place 5–17 months (mean, 11 months) after the death of the family member. We conducted all interviews in the home of participants or at a place convenient to them. The interviews lasted from 1 to 3 h, were audio taped, and were transcribed verbatim.

We used Grounded Theory methodology (16–18) for interviewing, data analysis and sampling. Interviews were conducted in German and started with open-ended questions. We followed with more specific questions as themes emerged from the simultaneous analysis.

For data analysis, we used open, axial and selective coding. With open coding, researchers categorize data from interview transcripts into broad categories or themes. During axial coding, each category is characterized and the relationships between categories are examined. Finally, selective

Table 1: Characteristics of relatives and their loved ones who were pronounced brain dead

Relatives	n = 40	Brain-dead family member	n = 33
<i>Relationship to patient</i>		<i>Cause of death</i>	
Parents: Mother	9	Cerebral vascular insult	15
Father	6	Brain injury	12
Partners: Wife	10	Suicide	2
Husband	3	Long-term illness	1
Children: Daughter (in law)	3	Other	3
Son	3		
Siblings: Sister	4		
Brother	1		
Grandmother	1		
<i>Age in years</i>		<i>Age in years</i>	
		4–19	5
20–39	12	20–39	10
40–59	20	40–59	11
60–79	8	60–78	7
<i>Organ donation: decision</i>		<i>Organs donated</i>	
Yes	31	Yes	28
No	9	No	5

coding includes organization of the categories into a framework to explain a phenomenon (19). Data analysis was facilitated by the use of the computer software winMAX (20).

The study was approved by local ethics committees, and all participants signed an informed consent prior to being interviewed. The credibility of the findings was tested by two relatives from the study group who read the results, and we presented the findings and hypotheses to three additional relatives from the quantitative sample. All five judged the results as mirroring their experiences.

Results

We found that the relatives' memories about their experiences may be conceptualized as their falling into the unknown and going through a process including multiple difficult stages, encounters with providers, and demands for which they had not been prepared. We will first describe the process with different stages through which relatives progress (see Figure 1), then the professional behavior throughout the entire process, as perceived by the relatives, and finally the variations of traumatic memories recalled as a result of the interaction between characteristics of the relatives' decision-making style (clear vs. ambivalent) concerning organ donation and the perceived professional behavior during the process.

Stages through which relatives progress

The first stage: The initial encounter: In every case, the process started with the relatives being confronted with a family member's anticipated or unexpected sudden, slow or abrupt health deterioration. The relative may have witnessed the catastrophic event or received the news secondhand from police, medical staff, another family member or others. Often in a state of shock, they traveled to the institution where the patient was treated. There they met providers who had varying levels of communication skills.

High emotional distress and conflicting information by different providers regarding the patient's status were characteristic of the situation. The risk of misunderstanding was high: For example, one woman was told in a peripheral hospital that her husband had suffered 'cerebral death', which she interpreted to mean that death had occurred. Upon arriving at the hospital to which her husband had been transferred, she was shocked to see her husband still 'alive' in the ICU.

Most relatives wanted to see the patient. One wife was alarmed: '*I had to wait first—I arrived in this unfamiliar territory—and was not immediately allowed to see my husband*'.

It was difficult for relatives to comprehend the situation both in terms of the status of the patient and the often rushed medical interventions by the providers. '*I cannot understand these beeping noises*', one relative told us.



Figure 1: Stages through which relatives progress.

'I am not knowledgeable about what the monitor shows—it beeps, and each time it causes this huge fear, since you know something is not right and you cannot do anything about it'. There were notable variations in the extent to which relatives felt acknowledged in their own right versus being seen only as a means to an end. As one relative said, 'I came and was told to wait in a small room. A young physician entered, greeted me and asked if I agreed to an organ donation. I said, "What is this? I first want to see my husband"'.

The second stage: Receipt of bad news: Bad news refers to the patient's bad prognosis, forecast with such physician statements as 'the situation looks very bad' or 'there is not much hope'. Bad news was told to the family at any time, beginning immediately after their arrival to hours later. Bad news was given in waiting rooms, physicians' offices, spare rooms, as well as outside or inside the patient's room. The bearer of bad news might have been the responsible provider or someone they had not met before. Bad news was, of course, difficult to receive: 'First, you feel some hope in seeing him lying there, but then you have to work through this news, this shock'.

The third stage: The confrontation with brain death and the request for organ donation: Although brain death and organ donation are different issues, relatives perceived them as inseparable, both conceptually and emotionally. For the purpose of discussion, they are treated below under separate headings:

Confrontation with brain death: While still trying to grasp the reality of what had happened, families were additionally challenged with making some sense of the diagnosis 'brain death' and its consequences for them. This challenge mainly comprised three aspects:

(1) *Learning new facts.* Explanations given verbally by providers or by means of documents, such as tests, were often perceived as fragmented bits of informa-

tion by relatives, which they needed to incorporate into their preexisting knowledge. None of those interviewed could reproduce a 'scientific' description of brain death. Rather, their narratives showed a variety of attempts to grasp the abstract concept.

We grouped these diverse attempts thematically as (1) Non-function: 'One saw in the pupils that cells did not function anymore. And he could not move at all anymore. Functions will not recover. This is death'. (2) Visibility/invisibility: 'From the outside you could not see anything. But I thought that inside, much, much must have died'. (3) Difference between brain death and coma: 'I had to ask, what was the difference between brain death and coma'. (4) Ambiguous reality: 'He is alive only because of these machines, but in reality he is dead'.

(2) *Dealing with ambiguities of perception.* Dissonances involved ambiguities between an individual's understanding of death and the impression of normalcy. One relative said: 'It was unbelievable. I see my husband lying there, well shaved, sun-tanned as he always is, breathing and breathing. It was like he was [still] alive!' Another remarked: 'There he was, alive with all these tubes. . . . It was such a shock; yet it was good that he was still alive in some way, since he was lying there as if asleep'.

Relatives' own ambiguities were either exacerbated or mitigated by the way staff behaved toward the patient. A son said to his mother: 'It is so difficult: on one hand, Father is brain dead, and on the other hand, they [the staff] talk to him'. However other relatives appreciated when the staff talked to their loved one when providing care.

(3) *Being uncertain about the moment of death.* Some relatives found it difficult to grasp when the patient was 'really' dead. Someone is dead, they told us, 'when the brain is dead', 'when the spirit leaves the body', 'when the organs are taken'. To be brain dead was 'being in a coma' or 'was not really being dead'. In one case, the parents had conflicting documents: 'On one she died on the 23rd, and on the other, she died on the 24th'.

Request for the organ donation: The topic was either initiated by the relatives themselves or by providers. Anticipated requests for donation were more acceptable than unexpected demands, the latter having been experienced as coming 'too early', as arrogant, or 'like a slap in the face'. Several issues played a role in relatives' deliberations about the request:

- (1) *Who made the decision?* Decisions by one person tended to be clearer than family ones. Family decisions depended on the opinions of different individuals and the family's ability to reach consensus on a decision with which they all had to live. Group decisions tended to be more ambivalent and/or tenuous.
- (2) *Their knowledge of the patient's stance on organ donation.* Seven families knew what their deceased relative had wanted. However, this did not necessarily mean that the relatives shared the patient's wish. Others assumed that the brain-dead individual wished to donate his or her organs, although they had never spoken about organ donation: 'My husband and I are scientists; it is clear [he wanted] to donate'.
- (3) *The relatives' specific beliefs about the body/mind and organs.* Beliefs that led to non-donation were reflected in such statements as '[the body] should be left in peace' or 'not used as a spare-parts repository'. Others believed that spiritual forces would still be present in the body or organs of their deceased relative and that organ donation would sever the connection between the deceased and the living. Donations and non-donations, alike, were motivated by special meanings attributed to the heart and the eyes: the heart as 'center of the person' or 'the seat of love', and the eyes as 'windows to the world' or 'expression of the soul'.
- (4) *Concern about who might receive the organs.* Relatives' feelings and values concerning possible organ recipients varied from no interest to strong, emotional convictions. One relative hoped that the heart would be given to a parent of children; another wished that a blind person might see again, thanks to transplanted corneas. Reluctant relatives, however, did not want organs to be given to 'someone unknown to you and about whom you know nothing of how he leads his life'. Others responded that organs should not be transplanted to a member of an ethnic group they disliked.

The fourth stage: Making the decision: When the time came for a decision, the options and outcomes were fairly limited. Relatives either gave a clear and unambiguous yes or no or an ambivalent and hesitant yes.

Clear decision: Clear, unambiguous decisions were likely if relatives knew the patient's wish and agreed with it, or if they themselves had a clear opinion. These decisions were made spontaneously, without much deliberation.

Ambivalent decision: Ambivalent and hesitant decisions resulted if the relatives followed the wish of the deceased to donate but did not, themselves, agree with organ donation; when they vacillated between no and yes or changed their mind from no to yes; if they had doubts that the organs would be given to a deserving person; or if a family was split in its opinion. In our research, we could not find relatives who refused to donate and were ambivalent.

Consequences of the decision: Not donating allowed them, if they wished, to stay with the patient until he or she was taken from the respirator and circulation stopped. Agreement to donation, however, meant that most relatives first took leave of their still 'living' loved one. Additionally when staying with the patient, they witnessed initial procedures of donor management.

Relatives varied in their wishes to stay with the patient after they had consented to the donation. Some did not want to see the patient, others left after a short good-bye, whereas still others stayed.

Some relatives who remained with the patient and witnessed donor management wondered if they had made the right decision. One grandmother, for example had doubts: 'They took lots of blood, made x-rays and so on and you start to doubt whether all these disturbances to the body are really necessary? ... What have I done?'

After the organ removal some relatives came back for a final farewell with the deceased. Seeing the corpse of their loved one was often described as a relief: 'After the operation I was able to see him once more, I was very happy' and 'seeing him cold was good since you cannot say good-bye when he is still breathing'. For other relatives, seeing the corpse gave certainty: 'Now he was really dead'.

Professional behavior throughout the process as perceived by relatives

The following two major styles of professional behavior were identified from the interviews (see Table 2):

Person-focused behavior: Relatives described 'person-focused behaviors' of the providers as behaviors centred

Table 2: Model of interaction between relatives' decision making style and professional behavior on relatives' memories

Relative's decision	Professional behavior	
	Person focused (n = 25)	Organ focused (n = 15)
Clear (n = 31)	Non-traumatic memories (n = 22)	Traumatic memories (n = 9)
Ambivalent (n = 9)	Non-traumatic memories (n = 1)	Traumatic memories (n = 6)
	Traumatic memories (n = 2)	

both on the patient and on the surviving family members' own needs. Relatives felt acknowledged if their loved one was treated with dignity (e.g. was gently being washed) and if their own needs for empathy, counseling, information and quiet or rest were considered. In one case, the parents of a child, after organ removal, wished to see the incisions on the body. They were accompanied by a nurse who stayed with them as long as they needed to be with their dead child. As one woman said, '*I was impressed with the health care providers. . . . I never imagined that they could be so good in the emotional realm; it made it a little easier*'.

Organ-focused behavior: Other relatives perceived providers as primarily preoccupied with medical questions and procedures, with acquiring their approval for organ donation, or with the task of preserving the organs. Relatives may have felt '*in the way*' or '*disturbing procedures*'. Some accused themselves later of having abandoned their loved one because they had '*obeyed*' the providers when they were sent away. In the words of one young man: '*After he died, we would have liked to light a candle and be with him undisturbed; but after 5 minutes, quick, quick, quick, we were out*'. In one instance, after the family had refused organ donation in the evening, an ophthalmologist called next morning to ask if the corneas could, nevertheless, be removed.

Relatives' memories

We defined memories as traumatic if relatives spontaneously reported or exhibited at least three of the following: (1) flashbacks or nightmares concerning their stay on the ICU; (2) intense psychological/physical reactions during the interview, e.g. uncontrolled crying; (3) avoidance of thoughts, activities or places related to their stay on the ICU; or (4) symptoms indicative of autonomic arousal, e.g. hypervigilance.

Whether memories of the relatives were traumatic or non-traumatic seemed to depend both on the decision-making style of relatives (clear or ambivalent) and on the behavior of professionals they had encountered (person-focused or organ-focused; see Table 2). Specific examples follow.

Non-traumatic memories: *Clear decision and person-focused behavior:* 'We both agreed to donate, just not the heart. From our church, we got the last blessing—I have to say, in the hospital everything went well—they changed her from a four-bed to a single room. We could be with her in private for the ritual'.

Ambivalent decision and person-focused behavior: '[The patient's] greatest fear was organ trade, he felt very strongly about it. Two physicians took their time, sat with us 2.5 hours and really explained everything to us. . . . They gave us time to discuss things and offered psychological support if we needed it. It went very smoothly'.

Traumatic memories: *Clear decision and organ-focused behavior:* 'We clearly said no to organ donation but the MD said: You have a healthy child, with a healthy heart and lungs, but he is brain dead. . . . his healthy organs could be very useful to somebody else'.

Ambivalent decision and organ-focused behavior: '[The patient] had told me she wants to donate. . . . Neither I nor her parents wanted to donate. . . . When the machine beeped, no nurse was there. The first times I got someone, but the nurse said "it is no problem". But when it beeped next door. . . . ten people rushed in like mad. It hurt me very much, since no one even bothered to look into our room'.

Ambivalent decision and person-focused behavior: 'I was glad they gave us time to think about [organ donation] and to discuss it. We were hesitant when his brother said: "But mother, if he cannot live any more. . . . worms will eat him?" In my head, it became clear [to donate] but (emotionally) I was totally shaken: we just cannot cut him and take these things out—I barely survived it. . . . We wanted them to treat our dead child with respect, which they did. . . . and since then, I have asked myself a 100 times if he was really dead or if we killed him by consenting'.

Discussion

Most research on the relatives of potential organ donors is focused on factors that may affect families' consent to organ donation, with the aim 'to maximize the possibility of persuading families to donate the relatives' organs' but may neglect the potential negative effect of the organ request on the future mental health of surviving relatives and loved ones (14). Our qualitative results confirm those insights of quantitative researchers who have discussed the importance of certain factors for a positive decision for organ donation. Such factors include (1) relatives' belief that the patient would have wanted to donate, (2) their own positive attitude toward organ donation, (3) the type of explanation about brain death received by professionals before the actual organ request and (4) relatives' perceptions of the requestors as sensitive to family needs and taking the time to discuss the issue (9,14,21–23). Our research adds further evidence that poor interaction between professionals and relatives can create traumatic memories about the organ-donation request (24–26). Our findings suggest that relatives' ambivalent decisions toward organ donation constitute a risk factor for traumatic memories, which can sometimes be prevented by appropriate person-focused behavior of professionals. However, our hypotheses concerning memories of relatives (see Table 2) require verification by means of a quantitative research approach.

It is possible that memories, accompanying both the brain death of a loved one and decisions about organ donation, may result in posttraumatic stress disorder (PTSD), which is characterized by intrusive thoughts, nightmares

and flashbacks of posttraumatic events, avoidance of reminders of the trauma, hypervigilance and sleep disturbance (27). Although screening relatives for PTSD by standardized instruments was beyond the scope of this qualitative study, traumatic memories, as reported to us, may indeed suggest the likelihood of the presence of PTSD among a number of our interviewees.

The sudden, unexpected death of a loved one is the trauma most often reported as the event precipitating PTSD in the general population (28). Recent research suggests that the risk of PTSD is increased in relatives involved in end-of-life decisions: Azoulay et al. (29) assessed the risk of post-traumatic stress symptoms in families of patients who had died in the ICU: 50% reported posttraumatic stress symptoms 90 days later, with higher rates among family members whose relatives had died after making end-of-life decisions (60%) and who had participated in end-of-life decisions (82%). Among a sample of 103 donor families, 17 out of 41 American families and 1 out of 62 Japanese families experienced PTSD after organ donation (30). It remains unclear if the request for organ donation, itself, represents an additional risk factor for PTSD. To our knowledge, there are no available findings that compare the incidence of PTSD in families asked for organ donation from their brain-dead relatives versus families whose loved ones died on the ICU.

In a survey of relatives of intensive care patients who died, 30% of the respondents were dissatisfied with the information given regarding the cause of death (31). These relatives indicated that they desired more psychological support beside the usually given information and explanations. The favored professional communication style seems to be in line with what our participants described as person-focused behavior.

We have integrated the reporting of our results into the Swiss adaptation of the European Donor Hospital Education Program (EDEPH), a one-day skills-training workshop aimed at training ICU professionals to communicate with bereaved relatives and to request organ donation (32,33). Participants report that our findings reflect their own experience when dealing with relatives. Our model of interaction between relatives and professionals inherently appears valid for most participants of the training course and enables them to better understand the impact their own communication style may exert on the nature of long-term memories of family members. Therefore the model may serve as an additional motivation to reflect and improve the individual professionals' communication style.

The narratives of our study confirm the necessity that health-care providers, when dealing with family members of a deceased brain-dead patient, be fully present, listen carefully and allow time for dialogue (34,35). Requesting organ donation is a difficult task and must be handled sen-

sitively and with compassion, so as not to bring any further harm to relatives by the urgency of the request.

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