

## Chapter 4

# A Sense of Absence: The Staging of Heroic Deaths and Ongoing Lives among American Organ Donor Families

Anja Marie Bornø Jensen

*I know he is not dead. He is alive in other people that are out there today. He is just not with me, but he is out there in other people... And that for some reason has given me great solace, knowing that other people are benefiting from my son's death instead of just putting his body in the grave and saying goodbye. And that is the end of it. That is not the case.*  
(Donor Father)

### Introduction

This chapter deals with particular human encounters of absence and loss as they are expressed by the families of American organ donors. After tragically losing a family member and saying yes to donation of the organs, many of the families of organ donors formulate perceptions of life, death, and organ donation that seem to insist on the continuing existence of the dead donor in different ways. These ideas are mainly structured and encouraged by the American organ organizations, supporting donor families in the time after the organ donation and wishing to transform the traumatic experience of losing a family member into positive sense-making stories about organ donation.

Suffering from a loss all the while finding a meaningful purpose in having given organs to others initiate peculiar paradoxes of grief and joy, death and life, and pointlessness and purpose among the involved families; paradoxes that call for anthropological investigation. Exploring these analytically through notions of presence and absence will be the purpose and challenge of this chapter.

According to Eelco Runia, presence is “‘being in touch’ – either literally or figuratively – with people, things, events, and feelings that made you into the person you are” (Runia 2006: 5). Dealing with commemorations, remembrance or the fascination with memory, Runia argues that when people attend the Vietnam Veterans Memorial or the reading of names of the dead at the World Trade Center,

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A.M.B. Jensen (✉)

Department of Anthropology, University of Copenhagen, Copenhagen, Denmark  
e-mail: anja.jensen@anthro.ku.dk

it is not in search of meaning, but rather in search of “presence”. Runia also claims that while presence is the denotative side of art, consciousness, and life, meaning is the connotative side (ibid), the point being that meaning is a specific way of defining or understanding presence. The point is also that presence is as important and foundational as meaning, and we have to recognize the “need for presence” which is not always (only) a struggle for meaning, but can be “an attempt to create an enduring and enjoyable intersection of both meaning and presence” (ibid). This chapter will embrace this understanding of the coexistence of presence and meaning, but at the same time discuss how meaning can also be the connotative side of *absence*. Specific interpretations and constructions of “being absent” can be as meaningful or sense-making as “being in touch”, as we shall see from the case of American donor families interacting with an organ organization commemorating the organ donors. From this context, I will argue that “being absent” is not the opposite of “being in touch”, it is a premise. Regaining or maintaining the presence of the organ donor would not be possible without the inevitable absence following death. What is central is how absence is staged, negotiated, and understood. From this empirical context, I shall therefore explore the intersections of absence and meaning, the ongoing dynamics of presence and absence, and learn how the organizational staging of organ donation can be understood as a search for specific sense-making domains of absence.

The chapter is based on anthropological fieldwork among donor families organized in the New York Organ Donor Network (henceforth NYODN or the organization). NYODN is the organ procurement organization of New York City. It has approximately 120 employees, and it covers all aspects of organ donation and transplantation such as PR and communication, encouraging the public to sign the donor registry, approaching families for consent, coordinating donation and transplants, cooperating with hospital intensive care units and transplant centres, offering support to families after the donation, and hosting a volunteer department consisting of both donor families, organ recipients and other interested parties that are trained to do public speeches about their personal experiences. My fieldwork was located at the Donor Family Services department of NYODN, referred to as “Aftercare” in daily speech. “Aftercare” is a concept that has spread across the entire United States after intense lobbying over the last 20 years from American donor families active in the “National Donor Family Council”. The council has worked intensively to put donor families and their special needs on the medical and public agenda, for example by writing a grief support book for donor families, making education programs for intensive care nurses, and by officially defining “The Donor Family Bill of Rights”, making sure that families of donors are entitled to decent care, support, and information during and after the process of donation. The concept of Aftercare can be best described as an organizationally structured support program offered to families after their consent to donate.

In New York, the two-year program consisted of bereavement cards, letters of thanks from the President of the NYODN, phone calls to the families, information about the organs, invitation to social events and acknowledgement ceremonies. In addition, the Aftercare program offered options to communicate anonymously with the organ recipients and an ongoing opportunity for the families to call the Aftercare

Department with any questions or concerns whenever these may arise. The talks could concern doubts about whether brain death really meant dead, the wish to know what went on in the operating room where the organs were removed, the desire to hear how the organ recipients were doing, or they could express a mere need to talk to somebody who is there to listen and show understanding no matter what. In this organizational setting, it became evident that the purpose was not only to take care of donor families, it was also to create, shape, and stage certain stories of absence and link personal grieving with an organizational purpose.

## **Staging Absence: Organizational Sense-Making**

Among the NYODN staff members, I often heard two foundational sentences expressing the organizational philosophy about donor family aftercare: The first was: “Donor families are our best advocates”, and the second was: “If donor families have a good experience with organ donation, they will tell 50 people, if they have a bad one, they will tell 500”. Hence, the organization had a great strategic interest in making sure that the positive family stories were promoted, and the negative ones were transformed into something else or silenced. To meet this goal, the organization provided donor families with a certain specialized terminology in order to help them speak about the donation and articulate the painful emotions of losing a loved one and making the decision to give the organs to others. According to the Manager of the organization, one of the major ways to support the family was to “provide them with terminology” to speak about it all. Over the years, the Aftercare Department had learned from donor families what worked for them, and hence they were not afraid to introduce that to newly bereaved donor families. This terminology would for example be statements such as “organs are gifts”, that organs were “recovered” not “harvested”, and that their loved one is “living on in the spirit”, and will “never be forgotten”. The specific use of words acted to provide families with the right value-laden terms to classify their actions. Anthropologist Michael Jackson argues that when people make words stand for the world, it is possible to manipulate ones experience of the world (Jackson 2002:18). Following this line of argument, organizational aftercare for donor families manipulates families’ devastating experiences and transforms organ donation from being associated with tragedy into being a “gift of life”. Language has taken over and manipulated and reinterpreted the experience into something sense-making, a much different perspective than the tragic devastating circumstances, usually preceding the decision to donate organs.

One major purpose of the Aftercare program is to present families with organizational values regarding organ donation and structuring and redefining their experiences from the hospital. In doing this, the organization not only provides families with rhetoric tools to describe death, the decision to donate and the outcome, it also structures families into a specific group defined by the term “donor family”. A major part of the Aftercare program is to introduce families to this term and make them adopt their new organizational identity. Many families in the organization embraced their new category immediately, and they regarded and presented

themselves as “donor families” first and foremost because it was a meaningful way for them to justify constantly talking about their dead family member. However, other families did not accept the term to the same degree, because it implicitly implied an acceptance of the organizational understanding of organ donation that was not shared by all families having gone through it. For them, however, there was no other choice than to remain outside the organization. The term “donor family” was organizationally created and not up for discussion. Coordinators openly stated that “donor family is our term, not theirs” suggesting that they were aware that families should be guided into this new identity that carried a tremendous aura of sympathy, respect, and acknowledgement. The staff at Donor Family Services made sure to communicate the organizational value that donor families had done something extraordinary and are considered very special while showing understanding, empathy, and respect through long conversations with families over the phone. During one of these phone conversations, I heard one of the staff members saying the following to a mother, who had lost her daughter:

I can't imagine how it must be to lose a child. You always imagine that you go first. You should know your daughter is a hero to many people. She saved the lives of six people. You should be very proud that she was able to help these people. You did the right thing. I will send you a package with some stuff that might help you deal with the grief. Again, I want to offer you my condolences. It is an honour to be able to speak to someone like you and your family. (Donor Family Services staff, phone conversation with donor mother)

As shown in the above quote, expressing empathy and admiration was important elements in how the organization communicated with the bereaved families. The emphasis on doing “the right thing”, the right thing being to save other people's lives, is an organizational value that lies as the foundation for all the work being done in the organization. While having as a goal to help and support grieving families, this aftercare work is also done strategically in accordance with the purpose and the values of the organization; to promote organ donation to the general public and encourage others to make the same decision “to save lives” because it is “the right thing”. This particular organizational staging and understanding of loss and bereavement is what relates absence to meaning and what gives rise to a moral presence of the organ donor because it is his/her body parts that now inhabit the bodies of others. Absence and presence are the prerequisites of each other.

The organizational influence on the creation of donor family stories became evident to me during my participation in a Volunteer Training in NYODN, where donor families and recipients received training from two members of an organization called “Transplant Speakers” on how to build up and how to tell their personal story to the general public. The stories should contain an introduction stating who you were and where you came from, for example: “I am a donor mom from NYODN”. After that, families should have “the body of the story” with the personal experience of loss and donation and perhaps some tactful humor. Thereafter, families should deal with “myths and misconceptions”, for example by invalidating the myth that “doctors let people die to take their organs” or “donation disfigures the body and delays the funeral”. Families were also told to use up to date statistics on the waiting list number. Finally, the story should have a “close” where the storyteller should personalize it to

the audience, call people to action by encouraging them to sign the donor registry, and finally say thank you and invite people to ask questions. This event showed how families were taught to transform their individual experiences into shared organizational narratives with different content but following a shared structure. Almost exactly the same idea unfolds in anthropologist Vibeke Steffen's significant study of Alcoholics Anonymous in Denmark (1997). The stories have several functions: Creating a community among fellow sufferers, making stories recognizable to an audience, and reshaping and confirming the legitimacy and social existence of the organization.

However, in the stories of many of the donor families I spoke to, the statements of the organization had clearly overwritten their personal experience and dominated the families' public versions of their stories. But in more personal and confidential interview settings, both sides of the coin were revealed, and the coexisting understanding of organ donation as a triumph and a nightmare became evident to me. A donor father showed how the organizational slogan of "turning tragedy into triumph" was incorporated in the expression of his experience while later in the interview revealing that the visual idea of organ donation was tearing him apart and leading him to drug abuse.

It [organ donation] has helped us to come to the realization that this horrible incident was unavoidable, that he was involved in. And we took that tragedy and we turned it into a triumph by making other people's lives better because of Joey.

I had been drinking a lot, and I had been abusing legally prescriptive sleep medication, but I was not using it properly. And the reason I was using both, was because of the dreams I was having and the visions of Joey on the operating table that I could not get rid of (Donor Father).

The organizational orchestration of stories can therefore also be looked upon as attempts to stage certain perceptions of absence and presence. Joey should be remembered as a young man saving lives in death, not a maltreated body on an operating table. In order to have an acceptable organizational presence of the organ donors, they have to be absent in certain ways; preferably heroic and life saving, not as blood and flesh causing nightmares. The nightmare vision of organ donation, the doubts about brain death, the fear of having killed your family member by consenting to organ donation exist among many of the donor families I met. But the organization deals with this under private almost therapeutic circumstances and conversations, and in this process it emphasizes the brave and positive aspects of organ donation that some donor families find comfort in telling and retelling as we shall return to. A popular version of the story is the one of the "organ donor hero" that is able to transform senseless deaths into meaningful memories.

## **Transforming Absence: Constructing a Hero**

Then I went home to explain to my kids what had happened. And my daughter was only five and did not understand life and death, so when I told her, she cried, she begged and pleaded for me to take her to heaven just for one minute to say goodbye to Mom.

But my son was 13 and he understood what was happening. And when I told him that his Mom had died, he cried and cried and we hugged for a long time. In search for something to tell him, I started explaining organ donation to him and that she was going to be able to save somebody's life. Through his tears he looked up at me and said "That makes Mom a hero, doesn't it". And I said, 'I guess it does'. And from that day on, we think of her as a hero, as someone, who maybe ran through a burning building and pulled some people out before being overcome by the smoke and flames herself. And it is that, what has really gotten us through this whole grieving process. (Donor Husband)

In the NYODN, this idea of an organ donor being a hero was constructed or indulged with a therapeutic purpose for the donor family. Many donor families adopted this idea about the donor as "a hero saving other people's lives" because it reassured them that there was a purpose or a meaning to the death and it gave a socially accepted model for reinterpreting a tragic loss. For donor families in the New York area, the heroism of saving others often had a reference to the terror attacks on World Trade Center on September 11th 2001 (9/11) because the event still had a significant impact on them. They often incorporated their version of 9/11 into their stories about losing a family member and consenting to organ donation. This indicates a link between public disasters and personal traumas, as also touched upon by Jackson (2005) when comparing the loss of a public landmark to a loss in people's personal lives. After the attack, New Yorkers were in a state of shock, but at the same time they seemed linked closely together in what Jackson refers to as "reclaiming a sense of shared certainties and meanings" (Jackson 2005: 15–16). The hero stories of organ donation were often deliberately designed by the organization to relate organ donation to well known ideals of saving lives. By relating the idea of organ donation to 9/11, NYODN put its organizational agenda within this framework of the New York's "shared certainties and meanings" and thereby created a cultural truth about the heroism of organ donors that was nonnegotiable. This idea is similar to what anthropologist Glenn Bowman classifies as "identity reconstruction after trauma". His work on 9/11 explores the processes "which transform calamitous events into consensual narratives" (Bowman 2001: 17). I claim that the understanding of the organ donor as a hero could be seen as a "consensual narrative" within NYODN because it has the ability of transforming the family catastrophe of death into the social pride of organ donation.

Heroizing and focusing on the positive characteristics of a dead person is not confined to organ donation. However, organ donation adds new aspects to this post-mortual honoring because the death literally results in improving or saving other people's lives and in that sense it is a very tangible proof of the selflessness of the donor. The fact that some of the donors had actually taken an active decision to donate and talked to their families about it beforehand is what characterizes them as heroes in the eyes of the donor families and the NYODN who see them as role models for others. The heroic aspects of the stories represent what anthropologist and historian Peter Gibbon calls the "moral component of heroism": The hero serving as a model or an example (Gibbon 2002: 4). In the case of organ donors, the purpose is to convince other people to donate. In American campaigns for organ donation, the term, "be a hero, be an organ donor" is very popular. Hence, the hero stories of organ donation act as yet another deliberate organizational tool to control the experiences of donor families and promote a general idea of organ donation as a way of being absent in a heroic way and thereby maintain or regain presence.

Looking at heroism in a broader historical and societal context shows that, in the USA, the hero has often been connected to military deeds, but the word has been tainted with bad connotations because of ambiguous attitudes toward American soldiers during the Vietnam War. After the 9/11 attacks, however, the word hero has been revived across the nation in descriptions of the courageous deeds of fire fighters, police officers, rescue workers, and the passengers on board flight United 93 who fought the plane hijackers (Gibbon 2002: 63–65; Skimin 2005: 305).

Writing about organ donation in an Israeli context, anthropologist Orit Brawer Ben-David claims that in Israel, a heroic death implies giving one's life for one's country. A heroic death is defined as the death of soldiers in war when the personal body becomes symbolically part of the national body. Other types of deaths such as suicides or traffic accidents do not have social significance and are therefore not categorized as heroic deaths. However, consenting to organ donation can transform an ordinary way of dying into a heroic death deserving national attention and recognition (Ben-David 2005: 128). Notions of transformation were also an element among American donor families. A father told me that his son was in the American Air Force when he died, training to be a pilot, like his father. Now the son would never serve his country and save American lives as he (or his father) had planned to, but he was able to "save lives in death". Thus, through the optic of organ donation, a teenager was suddenly a national hero because his body parts were helping "84 people in 24 different states". The father made sure to mention this constantly during public speaking as a very tangible and quantitative fact and a way of reassembling the whole body of the son and preserving his presence in spite of the fact that he was dead. Thinking about the organs still being alive, the father could create a heroic future for the son, even if it was not the one he originally intended. Looking at this through the optic of presence and absence reveals that this staging of heroic death creates a kind of "absence with a future", which in some cases is more glorified and socially accepted than ordinary life would have been. In life, father and son had their disputes, but by way of the specialized rhetoric of organ donation, all conflicts are forgotten, and the dead son becomes present in his absence in a way that is controllable and in accordance with the father's original goals and ideas about the son's future. Of course, the father is devastated by his son's death, but it can also be argued that he is able to be "in touch" with his son in certain ways because he is dead which exemplifies my initial point that in this context, absence is a premise for being in touch.

## **Commemorating the Dead: Objects of Acknowledgement**

In order to meet the donor family's need for recognition, the NYODN made huge efforts to memorialize organ donors publicly and thereby acknowledge not only the decision made at the time of death but also the life of the organ donor. In the social interactions between donor family and organization, the way people engaged with certain objects played an important role. Families were presented and provided with organizationally designed objects to understand the concept of organ donation, to attach the organizational values to their personal experiences and to provide certain material



Fig. 4.1 Memory Quilt from New York Organ Donor Network. Photo by the author

means of remembering the dead. Such objects include specific brochures and pamphlets explaining organ donation, butterfly pins to symbolize ongoing life, coffee mugs, key chains, T-shirts and posters stating that organ donation is “the gift of life”, and certificates of appreciation sent to donor families. Two of the most significant objects are the Memory Quilt (Fig. 4.1) and the Gift of Life Medal of Honor (Fig. 4.2).





**Fig. 4.2** The Gift of Life Medal of Honor from New York. Photo by the author

The Donor Family Memory Quilt, a quilt where the patches are made by the various donor families to commemorate the donor, is always displayed at the ceremonies and events with NYODN. The patches of the quilt are created by the donor family and can show a picture or a symbol of the donor and are made in certain colors and styles families associate with the donor, according to his or her age, sex, religion, occupation, or hobbies as a way of representing their personalities. Occasionally, the patches are made out of the donors' favorite clothes. The memory quilt seemed to have a tremendous emotional impact on the donor families. The patches represent their loved ones, and the quilt is treated as a valuable symbolic object and handled with utmost respect. It represents the personal lives and stories behind organ donation and it represents the multitude and diversity among organ

donors and their families. But it also serves as a valuable exhibition object for NYODN that uses the quilt as a powerful and visual PR strategy in its efforts to promote organ donation.

The other item is The Gift of Life Medal of Honor, which is handed to donor families at large recognition ceremonies by representatives from the organ organization or famous organ recipients, in order to publicly thank and honor the donor and the family. Families are asked to line up, and while solemn music is played and pictures of the organ donors appear on a large screen, families shake hands with a leading person in the organization and have their picture taken with the medal. Sometimes, families also get to say the name and age of their loved one when receiving the medal. The medal is a tangible symbol of the honor associated with being a donor family; families are almost rewarded for their efforts and donors are treated like war heroes serving their country by saving lives. The medal serves as a strong organizational tool and a symbolic way to structure the idea of organ donation and have families think of it as heroic and brave – an act similar to dying on the battlefield. American soldiers are honored by their city or their country and receive medals, and so should organ donors according to the philosophy of the organization. This need for national recognition was expressed by many donor families since the heroism in the stories of the families was not exclusively confined to the urban context of the terrorist attacks; it also acquired a national character as this donor father expressed when explaining why he used the word hero about his son:

And I can think of nothing else other than standing in front of a bullet and getting shot for the President of the United States or something that a Secret Service agent will do that is more heroic than being an organ donor and having made that decision to let the medical team do whatever they need to do with their body to help other people to live. (Donor Father)

Families explained that it was a great honor to receive the medal, and it made them feel acknowledged by their country. This national acknowledgement can be a kind of relief for a family that may have had to answer many critical questions from their closest network of family and friends concerning organ donation. The national acknowledgement is materially manifested at the 10,000 square-foot National Donor Memorial in Richmond, Virginia (see Sharp 2006), and is acted out at national events where American donor families come together. At the recognition ceremony for donor families at the so-called Transplant Games in Kentucky 2006, guards in uniforms marched in carrying the American flag accompanied by a rendition of “Amazing Grace”, and the audience pledged allegiance to the flag and sang the National Anthem. Thereby, the gratitude expressed toward donor families from the stage symbolizes the gratitude of their country and not “only” of the recipients or the organization staff. The national acknowledgement manifests itself in the fact that all American donor families are invited to Washington once every second year to the National Donor Recognition Ceremony. This ceremony includes the same elements as described above but, according to donor families, it has even more significance and a larger national context since it is held in the nation’s capital with the National Guard presenting the flag and playing music. The medal therefore was a very important object because it reinforced a national attention to the life that was lost, served as a cultural and political approval of the idea of organ donation in spite

of occasional personal nightmares about the procurement of the organs, and it communicated the need to make the donor and their families visible and present to the American public. Even though organ donation is more evident and visible in the American public media compared to other countries, the American organ donation community still demands more public attention and recognition in their quest for awareness.

Some American donor families also engaged actively in discussions on how to make use of and present these objects. During a meeting in the Donor Advisory Council in the NYODN, families discussed a suggestion posed by the organization to have the Gift of Life Medal sent by mail to all families instead of handing it out at the yearly Recognition Ceremony for donor families. All families agreed that it was better to present it to the families at the ceremony, the argument being that otherwise it would lose its value. This indicates that the value of the medal lies in the ritualised act of receiving it and not only in the object as such. A mother of a donor explained how she would not consider it an acknowledgement if she received it in her own home. The medal would never acquire its intended value by being sent by mail to a private home. To her, it was very important that the medal was presented to donor families in a public setting where the donors could be remembered. This discussion about the medal indicates the significance of the national state or the public to be present in the interactions with donor families. It also points to one of my main arguments, namely that it is in the social and ceremonial performances of the Gift of Life Medal of Honor and of the Memory Quilt that families are able to generate the feeling that their loved one is not forgotten, but still present in private, as well as in public memories (Jensen 2007). The presence of the dead donor has an important feature which will be elaborated further after having explored the significance of the organs living in others.

## **Living in Others: Durable Body Parts**

The substantial attention given to what is often seen as an alarming lack of organs in many Western countries and the ensuing potential commodification and reification of human body parts worldwide have been widely discussed in the social sciences for decades. This has been described as a process of objectification, devaluation, or dehumanization and considered problematic by many anthropological authors dealing with both organ trade in third world countries, the concept of gift exchange in organ donation, and the problematic of brain death (Alnæs 2001; Appadurai 1999; Fox and Swazey 1992; Healy 2006; Kopytoff 1986, 2004; Lock 2002; Scheper-Hughes 1996, 2004; Sharp 1995, 2000, 2001, 2006). One can argue that the premise for the transplantation business is that the individual lives of donors are reduced into body parts. However controversial this might be, the transformation of personal subjects into desired objects (body parts) should not necessarily be looked upon as devaluing human life or as some kind of identity depreciation. Looking at organ transplantation through the optic of presence and

absence illuminates something else. In the world of the bereaved, the transformation of a person into an object for transplantation is simply a necessary premise in order for the deceased to regain the subject status and for reclaiming a *particular kind* of presence in spite of death. Therefore, the categories of subject and object are not antipoles; rather, paraphrasing Latour (1993), they come together as hybrids, which can be an interesting way of looking at the body parts of organ donors.

In his influential book from 1986, Arjun Appadurai argues that things have social lives and can have different meanings and statuses according to context (Appadurai 1986). Lesley Sharp has developed this perspective in the realm of organ donation, claiming that an organ can simultaneously embody the essence of a loved one, be a gift for a recipient in need, and be a needed object of surgical desire (Sharp 2000). Therefore organs, like other things, contain a multitude of meanings according to shifting perspectives. From the perspective of the donor family, the meanings associated with organs change over time. At the bedside when trying to make the decision whether to donate, some families regard the organs as things that cannot be given away, or, paraphrasing Weiner, as “inalienable objects” (Weiner 1992). Other families regard the exchange of organs as a means to ensure the ongoing survival of their dead loved one. One donor mother told me that she found comfort in the fact that she did not have to bury everything when her son died. Knowing that his organs were still out there in other people helped her in her grief and gave her a sense that he was not entirely dead. For her, donation was a means of maintaining her dead son’s presence and thus of surmounting absence and death. Another donor mother expressed the idea of ongoing body parts like this,

I met Jenny’s heart recipient. Her name is Alice. What a cute little lady she is. The first time I met her, she said ‘I have this energy I have never had. When I wake up I have this urge to go rollerblading. I just have this energy. My husband has to sit on me and say no Alice you are not ready to do this’. Jenny rollerbladed all the time. Jenny was a karate expert. And I wonder. Do the characteristics, do parts of Jenny still live? It is a good feeling that a part of her is out there rollerblading or doing karate or whatever. (Donor Mother)

This focus on organs carrying personal characteristics and still living on appeared helpful to some families. The idea of a pounding heart functioning well in another body was perceived as solid proof to the families that death had occurred, but that the death was not to be understood as final. To grieving donor families, the organ recipients are the concrete evidence that the characteristics of the donor or the “life” in some peculiar way, goes on because of the use of their body parts. This corporeality seemed to be the most meaningful way for the bereaved to keep the idea of the donor still being “alive”. Because of this focus on the body parts, many donor families feel that they are luckier when compared to other families who have lost kin. The knowledge that the organs are alive in other people is a tangible way to deny death and absence, and keep the idea of presence through a pounding heart or another organ. A donor mother explained it like this,

I have people living today, who had that second chance in life that my daughter was able to give. It’s the most healing thing to know that Mary’s memory and her legacy will live on

through other people through years to come, through the woman who received her heart on to her children on to her grandchildren on to her great grandchildren. (Donor Mother)

Statements as these show the importance of looking closer at the notion of future lives and imaginations of kinship. By way of the organ recipients, the daughter and by implication her mother become a biological factor in reproducing their own family and the recipients' families, thereby creating new lives and new generations.

One father stressed the idea of the durable nature of the body parts of his late young son when he himself needed a bone implant in his back because of a spinal injury. He went to the tissue bank where the bone of his son was kept, only to find out that everything had been used. After at first being disappointed that this biological connection to his dead son could not be (re)established, it gave him a feeling of pride that the bones of his son were of high quality and in high demand. What this father did was to focus on the tangible materiality of the body and the high quality of the body parts, and the fact that they are functioning well in other people. This utilitarian perception of the late son's body is, however, simultaneously turned into a reinterpretation of the son's qualities and achievements when he was alive. Through his absence in death, the presence he had while he was still living was recreated.

However, organ donation can also create more disturbing notions of absence and presence that were not as widespread or directly spoken of in the organizational reality: What if the body parts were wasted and never transplanted into others? Families who chose to donate were often very sorry to hear if the organs were rejected by the recipient or if the recipient died right away. Some families were also told at the hospital that the organs could not be used because of hidden diseases such as cancer, HIV or hepatitis. These families were officially classified as donor families because, as the Aftercare Manager said, "we try to explain that the gift is real whether or not there is a transplant outcome". But even though the organization appreciated the intention to donate and not only the eventual outcome, it was the number of saved and improved lives that really made a difference for donor families alongside the notion that the organs had actually been transplanted into someone. A woman who donated the bone and tissue of her mother was very afraid the parts of her mother were not usable and were "stored in a freezer somewhere". This terrifying vision was rooted in the fact that she felt that families who donated organs got more organizational attention and acknowledgment than families like herself who "only" donated tissue and bone that were not considered quite as life-saving as solid organs, even in spite of the organizational attempts to neutralize this difference. This shows that along with certain notions of absence, there are also certain notions of presence that are more tolerable than others. Presence in other bodies and in other lives was sense-making to many donor families, whereas the idea of wasting organs could be understood as adding another painful level of absence on top of the absence caused by death. But yet another dimension needs to be added to the context and understandings of absence and presence within organ donation. In the performance of donor family

stories, organ donors regain their presence not only in a bodily but also in a spiritual sense, and they are not the only ones having their presence reconfigured by way of organ donation.

## **Performing and Pursuing the Presence of the Dead and the Legitimacy of the Bereaved**

I always remember somebody saying, that a person is only dead when you stop talking about them. That has always stuck in my mind. (Donor Mother)

I don't like the term 'lost'. I did not lose my daughter, she died. I know exactly where she is. To me, that is the only way that I can cope with this. (Donor Father)

The stories, the choice of words and the repertoire of expressions communicated by donor families help create what I call a “narrative presence” of the donor. And perhaps to some donor families, it is felt and experienced on stage as a more tangible presence. It is through the performance of the stories, what Edward Bruner calls “the expressions of experience” (Bruner 1986: 6), that the dead organ donors come to live and the family members feel they can still do something for their dead kin. Bruner argues that it is in the performance of an expression that culture is reexperienced, retold, and reconstructed and meaning is created (ibid: 11). Donor families are therefore able to regain various forms of meaningful presence of their relative, or to use Runia's definition, of “being in touch” with the deceased by performing the story of organ donation in the organizational context.

Hence, the organization not only shapes the structures and values for speaking about the organ donors; it also provides a stage on which the performance of presenting the deceased can be acted out without any questions. On this stage, there can be no such thing as the dead being lost or gone forever, to return to the quote above. The donors are dead alright, but they are still present because of the articulation of organ donation and their biographies. This seductive idea might be the reason why some donor families choose to speak about the death of their loved one over and over again. These stories and the strategic purpose they fulfill might not make sense outside the organizational context. But the particular context acts as a certain kind of social forum in which the dead can in fact become present through the revitalization of their spirit. Anthropologist Edward Schieffelin discusses something similar in his classic work *Performance and the Cultural Construction of Reality* (1985) where he examines the performance of nondiscursive spirit séances among the Kaluli people of Papua New Guinea. Scheffelin's work focuses on a completely different regional, topical, and cultural context, but his argument about performance is still helpful here:

Performance does not construct a symbolic reality in the manner of presenting an argument, description, or commentary. Rather, it does so by socially constructing a situation in which the participants experience symbolic meanings as part of the process of what they are already doing (Schieffelin 1985: 709).

In order for the absence of the deceased to become present in a meaningful way, a certain social situation must be established in which this performance is not necessarily perceived as a staging but as reality to families. And within the organizational context, the performance of the present dead is not a performance but experienced as a reality for families, marking a strong belief that the dead are present in spirit. It is part of their daily life in their involvement in the organization and to use the words of a donor mother, “the reason I get out of bed in the morning”.

Although the sense of the dead continuing their lives is of course generated by the surgical transfer of organs, I argue that living on could also mean something else that goes beyond the biological substance of an organ and beyond materiality. The dead live on through the spirit, through the donor’s legacy to use the words of the families. Statements such as “she was a very giving and caring person” provide families with a rational and logical way of explaining why organ donation was the right thing to do, and this could be a strategy of focusing on something other than and better than the tragic circumstances surrounding the death. Many families emphasize the altruistic character of the donor, by mentioning for example how he or she always cared for homeless people or made free wigs for cancer patients. Carrying out organ donation was a meaningful way for families to maintain this altruistic spirit and in a spiritual sense keep the donor present by constantly speaking about other positive aspects of their personalities that fit the narrative performance of giving.

Families maintained this spiritual presence of their late family members by constantly speaking about them. Speaking worked for the families as a way of easing the pain. It was therapeutic because it allowed families to experience a strong sense of the essence of the donor when speaking of him/her. They expressed how they felt the presence of their family member in the room while telling their stories. Some of them showed pictures of their loved ones while speaking and thereby ensured that the audience saw them too. To some, speaking about organ donation in the organization worked as a way of speaking with their dead relatives and addressing them directly. One donor father, for example, always said “this is for you, this is for you” to his late son when giving public speeches. The father meant, along with other donor families who chose to be involved in the organization, that his efforts of telling the story and promoting organ donation was what his son would have wanted him to do. And this fulfillment of what donor families chose to call the legacy reinforced the presence of the donor. A donor mother expressed how she felt the presence of her daughter,

So I guess a good part of it, I do it [speaking] for her, even though I am helping other people. I always say Karen is sitting on my shoulder. When I used to say I could not do something, Karen’s expression was always, ‘Mom go for it’. You can do it. It did not matter what it was. It was always ‘Mom go for it’. (Donor Mother)

Even though the public speaking reinforces the idea of an ongoing relationship between a donor family and the deceased, the dynamics of presence and absence were not only between life and death but also between anonymity and acknowledgement among donor families. Some of the families I spoke to stated that they did not want any remuneration for “the gift of life”, but they wanted something else that the organization was able to give them:

We want to be acknowledged, we want people to remember that if it were not for donor families, organ donation would not happen, so be gentle with us. (Donor Mother)

Looking back at the historical context of American organ donation reveals a struggle on the part of the donor families to be recognized as a group. The whole movement of American donor families has grown from a protest against being overlooked as a group. 25 years ago, donor families were not accepted as a group because they were a reminder that the transplanted body parts came from a living person, which could cause problems for the organ recipients who were told by doctors to consider the donated organ a mere spare part. The donor family involvement can be regarded as a way of defeating the anonymity of the organ donors in American society. Anthropologist Lesley Sharp (2001, 2006) shows that for many years, American donor families have chosen to make themselves and their dead family members visible and clarify to the public that organs do not grow on trees. They come from people with a life and a story and a family as is shown in the Memory Quilts mentioned earlier. American donor families show pictures, print T-shirts, tell stories, make quilts, plant trees, and lots of other activities to put a face on donation and keep the memory alive. Some donor families still recall participating in the Transplant Games the first year donor families were allowed to come, being housed several miles from the organ recipients and being ignored in the official program and in the social gatherings. Thanks to the effort of active donor family lobbyists over the last 25 years, this has changed. But some families still have an urge to point to their situation and remind us that they and their dead family member must be recognized. A donor mother made me realize this by referring to the concept of American heroes and introducing the idea of the silent hero which was how she looked upon her daughter.

We have our war heroes and then we have silent heroes: People who gave that gift. People like Jenny and any organ donor. They are heroes. Very seldom do you hear their name, very seldom do you put a face to that person – you hear – oh someone received an organ oh how wonderful. Do people think that these organs are in coolers in a hospital room somewhere? We talk about the transportation of organs in coolers. This is what the general public sees. And this is what they see on TV – carrying that cooler. Do they put that with a human being with a face and say oh my God it came from a 4 year old boy who fell down the stairs....

We honour our heroes every day. The war heroes. We hear how many are killed in the wars and I think – wauw you know – there are a lot more out there that need to be recognized. We cannot only hear the recipient side of the story. We have to hear the other side of the story and know that this is a good thing to do. (Donor Mother)

In conclusion, it can be argued that donor families struggle to maintain the presence of their loved one, but also their own presence as donor families as somebody who have lost the individuals providing the organs for the cooler. The position as donor family can be interpreted as a life transformation and new identity (Jensen 2007), and the families constantly reassure each other that they need to be heard and most importantly that the dead donors need to be recognized and memorialized. The paradox of the organ donors as being dead but alive in others; absent, but absent in a certain way so they regain presence, runs parallel with the justification of the donor family. Donor families are present as a category because of their absent family mem-



ber. And they have become more visible as a group as a reaction toward others' ignorance of their existence. They have become present by way of their public absence. Some of the donor families have experienced a life transformation and now have their primary social lives in the context of the organization where they can be among fellow sufferers or professionals sympathizing with them. Therefore, it is not only the organ donors who regain a presence in absence or in certain meaningful notions of absence. The whole conceptualization of donor families, too, can be understood within the dynamics of presence and absence. As with the revival of organ donors, absence in its many forms is the premise of the donor family's sense of presence; a presence that is constantly staged and negotiated, confirmed and reconfirmed in the organizational context. Thereby through a premise of "being absent", a sense of "being in touch" is achieved that is embedding the desire for recognition in a nexus of memorialization, commemoration, and "herofication".

In this theoretical landscape of presence and absence, one must remember that finding sense or purpose of the tragic death of a loved one will never erase the pain of losing, no matter how many lives are saved by organ transplantation, how many medals are handed out or how great an effort is put in by organizations or fellow sufferers. But this chapter has shown that the pain is somehow eased when the American organ organizations strategically provide donor families with a highly specialized social platform in which absence is not silenced, rather reinterpreted, transformed and articulated into something that can be rendered meaningful in the context of organ donation. Looking at this particular social performance, attention and recognition, one might argue that there is not only an "enjoyable intersection of meaning and presence" as stated by Runia (2006), but also of "meaning and absence."

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