

Organ transplantation as a “gift of life”? Interviews with young adult lung transplant recipients

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Lung transplantation has proven to be an effective therapy since the early 1990s for end-stage pulmonary failure caused by a variety of etiologies, such as obstructive lung disease, idiopathic pulmonary fibrosis, pulmonary hypertension, and cystic fibrosis. Along with the medical success psychosocial aspects have attracted attention, too. Most of the scientific literature on psychosocial aspects in lung transplantation today is devoted to “empirical” issues such as quality of life, to the relative neglect of the psychodynamics of organ transplantation (cf. [1]).

Even though quality of life is certainly an important issue, Margaret Sanner [2], a Swedish medical psychologist with a research focus on organ transplantation, has rightly emphasised, that the key feature of organ transplantation will not be addressed within such an approach. Organ transplantation is distinguished from other treatments to the effect “that vital, ‘living’ organs are transferred from one human being (deceased or living) to another” (ibid., p. 392). This inevitably poses great adaptive tasks to the recipient. Rauch & Keen [3] have once described these tasks with respect to the heart transplant recipient: “Although the old heart has caused pain and fear in most patients, its loss is felt. As with the loss of any body part or function, grieving for the missing organ, a vital part of the self, occurs” (p. 53; italics inserted). As the heart is particularly charged with meaning, the loss of “this powerful symbol and frame of reference for self-definition connotes a change in the self.” (ibid., italics inserted). Furthermore: since the foreign organs belonged to another human being “death pollinates the recipient's renewal” (ibid., p. 54).

Finally, many recipients “often behave as though the donor is still alive inside their bodies. Although this is partially true biologically, recipients may also believe that the new heart perpetuates the donor's social and psychological self. The felt intrusion of another person into the self may reverse separation and individuation processes. Recipients may harbour ideas of receiving the donor's traits” (ibid.; italics inserted). Not surprisingly, then, the “continuity, stability and nature of the self is threatened ” (ibid.).

Even though the situation may be particularly difficult in case of a heart transplant, the adaptive tasks are similar in other organ transplantations [2,4]. Given these challenges it is astonishing that there is little research on this issue.

We therefore designed a study with a focus on “transplantation through the patient’s eyes”, mostly relying on semi-structured interviews with 45 adult transplant recipients, 27 of whom were CF patients. The mean age of the interviewees was 32 and the mean time since transplantation was 5.5 years (12 months was the minimum time, set by our research design).

Non-CF recipients were age-matched in this study, because the course of their respective diseases would otherwise have resulted in markedly different samples (with non-CF recipients being about 10 years older than CF recipients; cf. [5]).

All interviews were tape-recorded and transcribed. We report here on interview findings specifically related to the topic which we initially outlined as the “pollination” of one’s own renewal by strange organs and by the death of an unknown donor. We analysed the transcribed interviews with respect to utterances which relate to the foreign organs (including the eventual transference of donor qualities) and or to the donor. Both aspects (organs, donor) will herein be summarized as the OTHER. The respective transcriptions were analysed according to the manner in which the OTHER was perceived (more precisely: was reported). Content analysis was performed by GU and SS who made independent ratings of the resulting main categories. The ratings proved to be satisfactorily concordant (i.e. reliable).

Results

As figure 1 shows, there were four main ways in which interviewees reacted to the challenge of the OTHER complex: responses showed a “neutral”, a “negative” or a “positive” perception of the OTHER or this aspect was neglected, altogether.

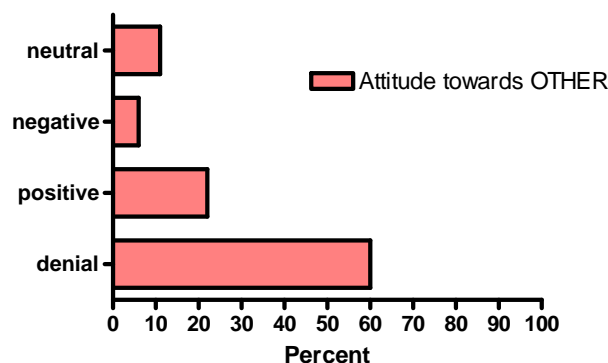


Figure 1: Valid percentages of the main response categories related to the perception of the new organs and or the donor, i.e. the OTHER

Utterances rated as “neutral” typically showed no tendency to deny the contact to OTHER, but the answers of the respective interviewee did not show a positive or negative connotation either. There were also a few responses where the OTHER was markedly noticed and appeared to negatively affect the recipient: the “tyranny of the gift” may be the most convenient heading for this. Some respondents frankly acknowledge the strangeness but talked about it in an explicitly positive way (e.g. that the new lungs were precious). However, as figure 1 shows, the majority tried to exclude the OTHER from consciousness, either by denying any strangeness of the new organs and or by declaring any thoughts about the unknown donor as non-existent or as futile (see box 1 for examples).

Box 1: Interviewees perception of the OTHER (Examples)

(Neutral) *“Well, it's not mine any more, but in a way it is mine, or rather, I just have to look after it. Even though it is not innate, it now belongs to me, and I have to look after it. And that's what I do”*

(Negative) *“Sometimes I have visions of a slaughterhouse, very detailed, ugly pictures. Not hospital-like, rather the pure and bloody organs, which are inserted to me. And then my blood runs cold”*

(Positive) *“Okay, for some time I felt guilty and I even thought it would have been better if the other person would still be alive. But then my new lungs appeared to me as something wonderful, because they allowed me to do so many things. And I thought: these are nice lungs and I always tried to imagine the donor and that this person must have been nice, too. And I started to experience my new lungs as something really precious on* me. That's how things evolved”*

“Well, some time after the transplantation, I had thoughts like: ‘Gosh, who might have been this donor?’ You know, I never tried to contact the relatives. I don't like that. I only wanted to get an idea of that person (...) Well, and occasionally I have prayed for her and I thought that perhaps you may feel pretty well in heaven, or so (...) Well, and I am very grateful for the donation. And sometimes, when I am just about to let me down, I say: ‘No! You owe to this person, to these lungs, that you... that I have to fight for life!’”

(Denial) *“I kept on thinking: they [the lungs] are mine”; “I never wondered [about the donor] and I don't want to know anything about him.”*

* Remarkably, the interviewee spoke of precious organs “on” her. In German this is a phraseology relating to clothing or other external material, only.

As the interviews were collected five years prior to this content analysis we wondered who was still alive, today. Remarkably (although not statistically significant), most of the deaths occurred in the non-CF group ($p=0.15$) and 7 out of 8 deaths belonged to the “denial” type

described above ($p=0.25$). If we included patients who were alive, but who experienced an organ failure necessitating a redo-transplant, the results were similar: 10 out of 12 cases (death and or redo-transplant) belonged to the “denial” type ($p=0.25$).

This frequent “exclusion” of the gift-of-life dimension in our sample is similar to the results of a British interview study on 31 CF adults (8 of whom were actually concerned with transplantation, either as recipients or as candidates, while the rest considered transplantation merely as an option in the long run). It may reflect a “‘spare parts’ pragmatism” that has been vividly criticized by Fox & Swazey [6], two medical sociologists who intensively studied the rise of transplantation medicine during the 1980ies and 1990ies. This rise seemed to be accompanied by a progressive ‘biologization’ of donated organs: “Increasingly, organs are being thought of as ‘just organs’, rather than as living parts of a person, offered in life or death to sustain the known or unknown others, that resonate with the symbolic meaning of our relation to our bodies, our selves, and to each other, and with the more than fleshly significance of what has been given and received” (ibid., p. 207).

The underlying “‘no problem’ sentimentality” (Fox & Swazey [6]) could be found in our interviews as well as in the UK-study performed by Karen Lowton [7] at the School of Medicine, King’s College, London. Lowton, however, clearly argued against Fox & Swazey and stated that this pragmatic attitude “is not profane, but rather a practical way of dealing with the transplant process” (ibid., p. 1363), i.e. it signifies successful adaptation. Our interviews confirm this interpretation. Contrary to the “‘spare parts’ pragmatism” that would imply a lack of sensitivity to the ethical and psychological challenges inherent in organ transplantation 90% of the interviewees in our study were markedly concerned about the respective problems of, for instance, living-related lobar lung transplant. Furthermore, 79% acknowledged that the ethical and psychological challenges might be a legitimate reason not to opt for a transplant – even though they themselves were strongly convinced of this treatment option. The latter is documented in a 73% rate of interviewees who would “certainly” decide to have a redo-transplant, should this be necessary. Only one interviewee refused to have a redo-transplant. However, even this person stressed that his refusal might not be definite, given the fact that he had initially refused to have a transplantation, at all. In other words, the real answer may not be given beforehand.

Given the fact, that interviewees in our study rather showed a “selective pragmatism” while maintaining sensitivity to other challenges of transplantation medicine suggests that their “denial” is part of adaptation processes.

However, even though the respective figures are low and statistical significance has (therefore?) not been reached, our results concerning “denial” and survival warrant a closer look at the functional or dysfunctional effects of this kind of adaptation. If other studies should confirm a respective trend towards inferior survival in recipients displaying denial, this would further support the conclusion of Margaret Sanner [2]. She performed one of the most thorough interview studies in transplantation medicine (comparing kidney and heart transplant recipients as well as living donation versus conventional necro-transplantation) and strongly argued in favour of a non-suppressive way of dealing with the OTHER. In her study, the “best defense” against fear of negative influence from the OTHER wasn’t denial, but the “creation of a benevolent donor” in the recipient’s mind (ibid., p. 398). This, however, requires to admit “odd” fantasies and feelings towards the OTHER. Finally, a more receptive attitude in recipients might be further supported by the staff: Sanner recommended that medical professionals should support strategies in line with the creation of a benevolent donor “rather than relying exclusively on suppression, avoidance and denial of the donor and the donation”



(2003, p. 398). This must include that “odd” fantasies and feelings are not disqualified as “irrational” fears. In the first author’s department (for minors, only) we regularly include art therapy as a very effective means to activate the (candidate’s or) recipient’s fantasies and feelings towards the OTHER or towards further aspects of the transplantation experience. There are no good reasons why adults shouldn’t benefit, similarly.

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