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At the Bedside

Ethical Issues Posed by Face Transplants

Edmund G. Howe

ABSTRACT

A face transplant is as challenging a surgical procedure as any patient can undergo. In this introduction I present the medical aspects of this surgery, the profound ethical issues it raises, and optimal interventions that clinicians can pursue to help these patients and their loved ones. I then discuss how to help other kinds of patients and loved ones who confront similar stresses. I end by presenting a goal that author Sharrona Pearl puts forth after she studied many face transplant patients. The efforts she urges should maximize our capacity to see face transplant patients—and anyone—as they are, as opposed to how they look.

In this issue of *The Journal of Clinical Ethics*, in "The Ethics of Psychosocial Assessment in Vascularized Composite Allotransplantation: A Call for Transparency of Process to Support Equitable Patient Selection," Laura L. Kimberly,

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Michelle W. McQuinn, Arthur L. Caplan, and Nomi C. Levy-Carrick discuss how we might best pursue equity for patients who receive a vascularized composite allotransplant.¹ These transplants use several kinds of tissues, such as skin, muscle, and bone, for transplants to the face, hand, and other areas.² The authors state, "VCAs such as face, hand, penile, and uterine transplant are intimately tied to individuals' sense of identity and are imbued with emotional significance. Although the heart may be viewed symbolically as a locus of the self, other solid organs such as the kidney, liver, and lung tend to be ascribed arguably less emotional import." These two sentences capture how singularly important such transplants are to patients. The first time I read them, I continued reading, even though I felt an ill-defined emotional discomfort growing within myself. I didn't know its origin. I thought that it might stem from reading about face transplants, but I didn't give the transplants a second thought. I continued to read, as if face transplants were like any other surgical procedure.

But they are not. They are as profoundly different a medical procedure as can be imagined. Thus, later, I felt shame for being so detached and indifferent. I asked myself, "Why didn't I pause to register or reflect on the uniquely profound nature of these transplants?" I determined that I was experiencing uncon-

scious denial. That is, I believe my mind was trying to protect me from the pain I might experience by even imagining what it must be like for these patients to want and have a face transplant. I thought that if this denial occurred within me, or even if it may have, that may be the case with others. Thus, I thought it would benefit readers, as well as myself, to explore face transplants and the ethical issues they might raise.³

The discussion will be in three sections. First, I will review some key medical aspects of face transplant and a few of the core, most far-reaching ethical issues they raise. Second, I will discuss the case of a husband and wife, “Paul” and “Rosa,” who participated in extensive interviews on their experiences during and after Paul’s face transplant.⁴ Third, I will discuss what we may learn from the experience of Paul and Rosa, as well as the experience of others, that might help these patients, and even all patients for whom we care. (There are only a small number of patients who have had a face transplant; just a few more than 40 at this time. Yet, for self-evident reasons, they must be among patients who are the worst-off. By looking at their reports of their needs and pain, we may see how we can better meet their needs and the similar needs of other patients.)

At end of this article I will add a thought that speaks not only to how we may help our patients, but also ourselves. This is not my idea. It comes from an author, Sharrona Pearl, who arrived at this suggestion after she reviewed the experience of many of the patients who have had a face transplant, which she recently published in a book.⁵ I will quote her extensively. Her urgings are aspirational; no matter how we try, we will never come close to accomplishing what she asks. This, too, is an insight we should seek to transmit, and it is an important insight should we ever care for a patient who has had a face transplant. Few of us will treat these patients, but this insight is applicable and potentially transformative for all patients, as well as for ourselves.

MEDICAL BACKGROUND AND CORE ETHICAL QUESTIONS

Medical Background

A face transplant would be considered when a patient experiences severe bone and soft tis-

sue facial loss that results in serious aesthetic, functional, and/or sensory deficiencies. These losses may occur as a result of an animal attack, burns, a gunshot injury, cancer, neurofibromatosis, or other causes. The first face transplant was performed in 2005. The outcomes of the surgery have improved greatly since then. These gains are due to many factors, such as advances using computers in pre-operative planning and improvements in surgical techniques.⁶ We know now also that nerve regeneration takes place faster than was initially thought. Thus, facial sensation and mobility can be restored as early as within months of surgery.

There are serious risks. First is the possibility that a transplant will fail over time, and then slough off. This horrific outcome occurred recently for Carmen Blandin Tarleton, who is well known in the United States for her courage, as she has, since her injury, conducted herself with the utmost regard for others in spite of what she experienced: 12 years ago her husband attacked her with a baseball bat and threw lye in her face.⁷ She had a face transplant five years later. Now, at age 51, her transplant is failing. The blood vessels beneath the transplant have less circulation, and, as a consequence, her facial tissue is darkening. Her immune system is rejecting the transplant. She is now faced with deciding whether she wants a new face, with a second transplant, if that becomes possible, or to accept going back to her old face. She would then look as she did prior to the first transplant.

Other serious risks exist. The surgery itself is risky. During surgery, patients may have massive blood loss. Patients may require sedation for 24 hours. They need to take immunosuppressive drugs for the rest of their life. These drugs may have complications, including increased risk of infection, diabetes, and decreased bone density, which may cause fractures. Patients may have no warning of decreased bone density until the first fracture occurs.

The decision to have a face transplant may be excruciating for many reasons. Because there are additional medical risks, the best time to decide to have surgery may not be right after patients’ facial trauma occurs. Patients may initially receive standard reconstructive surgery, which may leave them satisfied. At that point, they may feel that they don’t need or want a face transplant. The fear that a transplant may later slough off, or that they will always need immunosuppressive drugs, may be among the factors

that move them to not want a transplant. Yet, if a conventional procedure that involves free tissue transfer fails and patients then choose to have a transplant, there is a high probability that the vascular areas in the patients' head and neck surfaces have been compromised. Changes within the blood vessels may limit the degree to which they can nourish a face transplant. Earlier procedures may have caused facial tissue scarring and fibrosis. Connective tissue deposits may make a face transplant more difficult and challenging.

Some Core, Far-Reaching Ethical Questions

But the emotional severity of contemplating losing one's face may go well beyond this. Facial expression is at the heart of human interaction. Our face and voice are essential to being recognized as ourselves. We associate both our face and voice with our identity. Thus, patients may feel frightened when imagining how they appear and how others see them. Our face and voice affect, more than anything else, how we respond to each other. But it may be that we can do better. It may be that we can transcend the stereotyped biases that our face and voice—and others' face and voice—tend to create. I will discuss this possibility more at the end of this article.

A truth that is sometimes unrecognized is the overriding effect that our nonverbal interactions have, relative to what we say. That is, when our demeanor contradicts the content of what we say, listeners will, in most cases, respond to how we have spoken rather than to what we have said. A further, particularly dear loss that can occur when we lose the capacity to express ourselves facially is the loss of how we relate to those closest to us. Unwanted distancing may occur, and this may occur even between parents and their child. Later I will relate how this may occur when a child has been severely burned. Fortunately, as I will describe, there are ways to overcome this distancing.

Some patients who want a face transplant say they want the transplant because, without it, they will experience what they call "social death." Some have described this suffering as worse than death. That they report this experience suggests a first ethical question: Do we sufficiently prioritize the care of all patients who, to any significant degree, experience social

death? This loss involves a form of death of identity, as well. It is perhaps of no small significance that we use such expressions as "not being able to *face* ourselves" when we feel shame.⁸

This is the question I will consider in the first section of this article. I will present two paradigmatic examples of other kinds of patients for whom this question is most relevant. The first example is that of patients who are socially isolated because of their appearance. In this way, they are like patients who want a face transplant. The second example is that of a group who number in the millions: patients who may become isolated because of how their mind works. Others may see them as different due to an emotional illness they have or had, which causes others to label and regard them irreversibly as "other."

Social Death—What It Is Like

Patients may want a face transplant because otherwise they will experience what they see as social death. Why they feel this way is no mystery. The hurt others may inflict on them may be piercing. Others may say, for example, that they needn't wear a costume to a Halloween party, or that they are surprised they are getting married because who would marry them, due to how they look. Children may run from them in terror, as though they had seen a monster. Adults tend to be more subtle; they may, for instance, turn their face away or walk in a different direction.

Conversely, some patients who have experienced severe emotional trauma may have "invisible" impairments that may cause them bitterness. One person I see, for example, is so emotionally vulnerable and "soft-shelled" from experiencing severe trauma that, when another person so much as raises a questioning eyebrow, he flees like a child who runs in terror at seeing a severe facial injury. In a panic, he runs back to his home and stays in his bed, huddled under the covers, for hours or sometimes a day, until the intensity of his panic decreases. He says that others, for example, persons who raise an eyebrow at him, don't understand, and blame him for how he responds. He envies those whose impairment "shows," because others will more easily "get it."

Even so, those with an "invisible" impairment may not always be the worst-off. One person with visible impairments has said to me that *he* envies persons with invisible wounds. People

always seem to respond to him based on how he looks, and they often seek to distance themselves from him. He says this will be a reality for him for his entire life.

Given these examples, a first practical ethical question is whether we should give the needs of a patient who experiences any significant degree of social death greater priority than other patients. I will now give two examples of other groups of patients to whom this may apply. Both are paradigmatic of other numerous patient groups that may experience degrees of social death.

Transgender persons. A first group is transgender persons who have changed how they look so that their appearance accords with their gender, but whose appearance still attracts unwanted attention. This may be due to their voice, their facial hair, or their body. As an example of the last, they may need to avoid unwanted attention by having breast or chest contouring. For them, how they look, not how they are as fellow human beings, may determine how others, such as strangers, respond to them. This may leave them feeling isolated and blocked from being who they are. This need is also critical for patients who want a face transplant.

A core ethical question is whether the medical interventions transgender persons want should be provided at the public's expense when they are unable to afford the interventions. This could come about if we give their needs, and the needs of similar patients, greater priority because we are able to see the pain caused by social death.

Patients with emotional illness. A second group, which is much larger, includes all patients who have some degree of social death as a result of emotional illness. This occurs most commonly among people who have psychoses. By this I mean that at some time or other they have been unable to appreciate reality. These patients may come to feel socially isolated and as "other," even within their own family. This group, in its larger sense, includes many others. An especially illustrative group is patients who have an addiction. Their family members may regard them as always fundamentally flawed and as "other." These individuals would be the first to point out that even when their addiction is completely in remission, the risk of relapse always remains.

In both examples, helping these individuals and their loved ones, if possible, to escape

and reverse social death, although expensive, may be worth the cost. I am suggesting a new ground for this that could be conceptualized as "social death exceptionalism." Here I use "exceptionalism" to refer to a category that differs from others, and, on account of this difference, has different consequences. Thus, "genetic exceptionalism" would refer to the fact that a patient who has an illness with a genetic component may have to face the question of whether to share with others who have the same genetic component that the patient has this illness, when the others may not otherwise know this.⁹

Patients Who Want a Face Transplant: Trapped in a Catch-22

A subgroup of patients who want a face transplant may be worst-off among patients who want a face transplant. Members of the smaller group are those who want a face transplant but can't, even if an appropriate donor is available, because surgeons see them as too emotionally unstable and as posing too great a risk of a bad outcome. The basis of the surgeons' fears may be understood by considering the risk posed by patients who request cosmetic surgery and have wholly unrealistic expectations. If their expectations are not met, they may feel disappointed, "crushed," and even worse. Some surgeons refer to these patients' plight as a "catch-22" because patients who want face transplant surgery may, for that reason, be seen as not stable enough to have it; patients who are seen as emotionally stable enough to have the surgery may not want it because they can accept living and looking just as they are.¹⁰

Such a degree of self-acceptance may be a component of and reflect the patients' underlying emotional stability. An example of such a person is a well-known British magistrate who has and accepts his facial disfigurement and continues to work in this legal capacity. His portrait has been shown with those of many others, also facially disfigured, in a London art gallery. A description is as follows:

Mr. Lotbiniere's portrait, on a large wall directly opposite a glittering array of Mario Testino fashion photographs at the National Portrait Gallery, is impossible to miss, as is Mr. Lotbiniere himself. Cancer has robbed him of much of his face, giving it a startling lopsidedness, caved-in in some places, jutting out in others. Wearing the magisterial barrister's wig and gown of his profession,

Mr. de Lotbiniere gazes head-on from the canvas, his legs crossed, his expression unflinching, unapologetic and even faintly amused: a man, it seems, entirely at ease with his altered self.¹¹

A core clinical question that this catch-22 raises is whether patients who want face transplant surgery are sufficiently emotionally stable to have it. Given this, surgeons see the pre-operative psychological analysis they perform on patients who request a face transplant as no less important than the operative procedure they will perform. As one surgeon says, "Performing a thorough psychological analysis preoperatively is as important as surgical diagnosis and intra-operative precision."¹² Thus, a second core ethical question is, Should we do more to try to help patients who want a face transplant—and others like them—who cannot, for reasons other than expense, have access to the help that they need to reduce their experience of social death? As before, we will consider two examples of patients who have this exceptional need.

Patients who have caused their need for a face transplant. An uncommon subgroup of those who want a face transplant but whom surgeons deem as too unstable for surgery is patients who have damaged their face as a result of a suicide attempt. Surgeons may consider doing surgery on these patients too risky because the patients are seen as likely to repeat the injury.¹³ But probably the majority of these patients will get better and no will longer be suicidal. Assisting the patients may require greater and reprioritized societal resources, particularly if they are treated maximally by involving all of their family members in their recovery. As I will explain to a greater extent subsequently, clinicians who also treat their patients indirectly, by involving the patients' loved ones whenever possible, may go farthest in helping patients escape experiencing unbearable social death.

I will explain in more detail how profoundly patients' family members may help. Further, I will explain how it may not be possible for patients to escape where they are without the involvement of loved ones. I recall seeing a patient who had shot himself in the head and then had face surgery. A key part of his eventual recovery involved my also treating his mother. After the patient shot himself, she was terrified every time he said something that was less than totally positive. It was unlikely that he would

have recovered as fully as he did if his mother had remained wholly beset by her fears.

This example illustrates how we are, more than we commonly realize, social beings who are dependent on our social relationships with loved ones. This is the flip side of the pain inherent in social death. This man and his mother did well, in time, and I believe to accomplish this, each needed the other.

Patients with schizophrenia who are homeless. Another group of patients who lack access to the help they need to escape social isolation is homeless patients with psychotic illness, such as schizophrenia. These patients may live so socially isolated from others that they experience social death. With greater, sufficient allocation of our resources, however, they too may be helped.¹⁴ They may be less responsive than similar patients who are better-off socially. Thus, to give these patients the exceptional help they need may require our reprioritizing and increasing the resources we provide to them. There is an additional, critical point that should be made: even when we are medically limited in what we can do, doing what we can to relieve our patients' social death may still be a priority.

I recall in this regard a patient I saw who died some years ago. He had some psychiatric illness and had been homeless and had lived under a bridge. He recounted afterwards, endlessly, the pain he had while living through this experience. He returned to this so often, and to such an extent, that I wondered after some time whether ethically it made sense for me to continue to see him as often as I did. I thought perhaps that I might offer additional patients more if I saw him less. Then one day he said, as if only in passing, that his sessions with me gave him the sole source of meaning in his life. He lived for these singular opportunities to share what he felt, because otherwise he was mostly all alone. Hearing this I felt, I should acknowledge, more than a bit ashamed because I had not imagined this on my own. I decided to see him as much as I had been. Thus, this is a possible hidden presentation of social death. Our efforts to help patients reduce this form of death need not be all-or-none. This patient's relief was no more, I guess, than a smidgen. But it was, to him, though, some relief, even if far from enough.

Social death exists along a continuum. How might we prioritize our regard for all those worse-off in this way? If we ask patients directly

about their feelings of isolation, it may leave some feeling shame that it is so evident that they are socially ostracized. But if we pause long enough to acknowledge the pain they feel when they express this, it may help them feel less alone, even to a very small extent, afterwards.

PAUL AND ROSA

The couple I mentioned at the beginning of this article, Paul and Rosa, agreed to be extensively interviewed to describe their experience after Paul received a face transplant.¹⁵ Paul sustained extensive injury, including the loss of his sight, from a gunshot wound to his face. The researchers who interviewed the couple changed their names to protect their identity. The couple said they chose to describe their experience because doing so “may not only help to increase our understanding of the different psychosocial aspects of face transplantation, but also may inform professionals to optimize transplantation procedures or supportive interventions.” I report here much of what they said, to inform us in both of these respects. This may help us to better treat most or all other kinds of patients.

Helping Patients Learn Where to Focus

Paul noted that three things helped him cope successfully: focusing on the present, focusing on the smaller details of his life, and enjoying whatever he could.¹⁶ These approaches may help all patients. Paul’s focus on the present echoes the guidance given to many, to live one day at a time. This approach, philosophically, may be appreciated as classical Stoicism. Reminding ourselves to focus on the present may be beneficial. Paul’s focus on details also is instructive. Purposefully trying to shift our focus can help us relieve pain. One approach, for example, is to stop and quantify pain when we experience it. The shift in focus may distract us. Perhaps surprisingly, this may help us gain some relief. The practice of seeking to enjoy what we can, when we can, and building these rewards systematically into our daily experience also may help to reduce pain, sometimes considerably. We may benefit additionally by being able to look forward to such rewards.

The core notion here is not, however, these techniques. The core point is that these and similar approaches *may* help. Thus clinicians who do not specialize in knowing about these ap-

proaches should refer patients to other clinicians who know these techniques and can teach them, when possible. Learning how to use one’s breathing, for example, is particularly effective.

Clinicians who choose to refer a patient should consider saying before the referral that, for many patients, *none* of these approaches may be successful. Saying this may negate the possibility that clinicians will “prime” their patient with a positive expectation that may, in a placebo-like way, become self-fulfilling. More importantly, saying this may avoid the risk that the patient will perceive the clinician as trivializing the patient’s suffering by seeing such techniques as being able to do more than they can.

Telling Patients that They May Feel Better Later

I just mentioned a possible rationale for clinicians to give up a possible positive placebo effect to retain their credibility and their patient’s trust. But it may, as the same time, be possible to enhance a patient’s hope by sharing the positive gains the patient may experience. In interviews with Paul and Rosa, Paul said that the main reason he chose to have a face transplant was social. He wanted to regain his joy at interacting with others by regaining a more normal appearance. He succeeded. He said: “That you felt that your nose is normal, your lips, your chin. It was a very pleasant feeling. It is unbelievable that this was possible.”¹⁷

That patients may have such an elated response after a face transplant is, based on the few reports available, not uncommon. The number is small. There are, however, even in this small group, exceptions. Some patients miss their old face. Clinicians who see these patients before transplant may be able to tell them truthfully that they may feel more elated after transplant than logically they might expect, as Paul did. Doing so may help patients have hope at a time they especially need it. Clinicians may also tell patients, truthfully, what may be even more unexpected: that they may find new and different meaning in their life in regard to what “counts” most for them. One patient said that before transplant, “losing ten pounds” seemed as though it was “everything,” but after transplant, she found that it wasn’t that important.¹⁸ This possible new sense of meaning that patients can’t anticipate may help sustain them through difficult times. Clinicians may help patients

optimally by informing them that while this may occur, it may not at all be the case.

Patients who hear this caveat about having too much hope may, paradoxically, find that it increases their hope. They may feel better, and rightly so, because they know that their clinicians could level with them and not overstate the best case. Patients then will be better prepared and less disappointed if their best hopes do not come to be.

Loved Ones Can Feel the Love They Felt Before

Rosa said that she experienced her husband Paul's new face as a "miracle." She said that she no longer notices that his new face is not his original face. This possibility is another basis for patients and their partners to have realistic hope. Rosa noted, most significantly, that it was "crucial" to her that Paul's voice remained the same. This sameness helped her to be able to experience Paul as the "same person" that he was before surgery. She said, "in the end you go with the voice. It is the voice that you associate . . . and it is the same voice as before."¹⁹ Knowing in advance that a patient's voice may not change may help the patient, family members, and loved ones get through and beyond the rougher spots.

Give Patients and their Partners the Information They Want

Rosa said that although she was well informed about the surgery, she would have preferred to have had Paul's clinicians give them more detailed information about the possible benefits and negative side-effects. She would have liked, she said, to have been able to talk with others who had been through the surgery, if possible. Both points offer instruction. Rosa believed that the medical team might have chosen deliberately to *not* give them some information and to *not* arrange for them to meet another such patient or couple because the clinicians feared that, if they did, Paul might not have consented to the transplant. This lack of information may have resulted in a lack of trust.

Before surgery, clinicians may do their best to provide patients and loved ones with all of the information clinicians believe they will want. But later, patients and loved ones may

come to feel that the amount of information provided to them wasn't as much as they wanted to know. This may be because they did not know before surgery all that they might want to know, and it is only after surgery that they realize what they might have wanted to know.

Yet clinicians may understandably fear that they may provide too much information. Receiving negative information and talking with others could be discouraging, and, as a result, patients may choose not to have a transplant. Clinicians' fear may be especially intense if they feel strongly that surgery will positively change patients' lives, as it did Paul's and Rosa's, and leave the patients faring significantly better. Clinicians may be right in their prediction that patients' and loved one's quality of life will be improved. The problem then would be how strongly they should urge surgery to patients. Respecting patients' autonomy maximally usually requires giving them the information they want and even going the extra mile to introduce them to other patients, if possible. Further, if it seems to patients and loved ones that clinicians are withholding some truths, as it did with Paul and Rosa, this may diminish the trust they feel for their clinicians.

An approach that may be preferable under these circumstances is for clinicians to openly share their concerns with patients and loved ones. Then clinicians can tailor how they will meet the needs of patients and loved ones by working *with* patients and loved ones. Clinicians may, for example, ask patients whether they believe they will do well, knowing that they may be having some denial. The denial I may have experienced as I read about face transplants is an example of how we may experience denial. Based on what patients say, they and their clinicians can decide what to do *together*.

Take Seriously *All* that Patients Say

Both Paul and Rosa said that they felt that their medical team often minimized Paul's concerns. Both resented this. Their response echoes a frequent patient "complaint" that their clinicians do not take seriously enough what they say or reflect on it enough. Clinicians should obviously try to avoid minimizing patients' concerns. If possible, for example, clinicians should not interrupt patients repeatedly, and, when they must interrupt, for example, due to having other patients who are stressed and waiting, clinicians

can at least apologize to patients and explain why they have interrupted. Clinicians may also keep in mind that what patients say may be meant in two entirely different ways: they may be making a factual statement, or they may be just attempting to express how they feel. Clinicians who appreciate the last possibility may be less likely to dismiss what patients say on the ground that it is inaccurate.

Ask Patients *First* Whether It Is Okay to Ask Intrusive Questions

Paul said that he was comfortable with all of the questions his clinicians asked him, so long as these questions focused only on medical concerns. Had they asked him about more personal aspects of his life, he said, this would have been unacceptable.²⁰ There are often good reasons for clinicians to ask personal questions. Patients who have had a face transplant may, for example, have new difficulties in experiencing sexual intimacy with their partner, and clinicians may know ways to help them. Counter-intuitively, for example, if couples agree beforehand not to have sex, this may help men to regain the capacity to have an erection. A question that is always present, however, is whether the benefits of clinicians asking patients such personal questions outweigh the possible harms. A way to avoid, or at least lessen, the risks is to ask patients initially whether or not they would want clinicians to ask personal questions.

Be Open to What We May Be Missing

As a result of his injury, Paul lost his sight. Some clinicians who do face transplants for patients who are blind assume that their patients will have fewer problems resuming their social relations after the transplant, because the clinicians believe that blind patients will not see how others respond to them. This is in one sense logical, but in another way this may not at all be the case. Rather, patients who are blind like Paul may even more accurately hear others' voices and be able to sense just as much as a seeing person what it is that others feel.

Try to Connect Patients with the Clinicians that They Will See Later

Paul and Rosa reported that they found themselves switching again and again from one

clinician to another whom they didn't know. This occurred because Paul saw experts in many disciplines. In all, he and Rosa saw 65 health workers who represented 15 different medical specialties. They said that they often felt confused. They would ask, "Who's in charge and of what?"²¹ A possible way to help reduce this source of pain and confusion is to try to arrange some prior contact between patients and some staff members. Such contact may be with "just" a receptionist they will see when they first come through a closed door, but their knowing beforehand and then recognizing this person's name may go a long and surprisingly disproportionate way to helping the patients feel "welcome." Patients may feel much relief at this. Their relief may be substantial, and in this way disproportionate to the time it takes, which may be only seconds.

OPTIMAL SOLUTIONS: "OTHERS"

Patients may have to be sufficiently emotionally stable to have a face transplant, as noted above. They may need such emotional stability to be motivated enough to benefit maximally from the physical rehabilitation they will need to regain facial mobility, and the post-surgical speech therapy they will need to speak effectively. How may most patients best maintain their emotional stability, or acquire it if they lack it? I will present three possible approaches, all of which may apply to other patients, as well.

Help Patients' Loved Ones and, in this Way, Help Patients Indirectly

Patients, like any of us, may do remarkably well if they are fortunate enough to have another person who loves them unconditionally. Paul, for example, had Rosa. Day after day he learned from her that, to her, he was the same person that he had been before the face transplant. Regardless of what he might have accomplished on his own, which may have been most extraordinary, he could internalize her regard for him. That loved ones may be able to do this, however, cannot be taken for granted. Thus, if loved ones find themselves distancing themselves from a transplant patient and they ask clinicians for assistance, the clinicians should make it a priority to help.

How best to provide this kind of help? Laura Armstrong-Jones and colleagues illustrate one

way. They write about how six families of parents and children who were badly burned attended a residential “burn camp.”²² Summarized succinctly, the children, their parents, and the children’s siblings benefited immensely. The children learned again that they could have fun. They were able to talk, often for the first time, with other children without worrying about looking different. They were able to see other children as themselves, rather than seeing them only as children with burns.²³ Their parents benefited similarly. Notably, some parents, for the first time, overcame their feelings of guilt. They had irrationally concluded that they were at fault for their child’s burns, even when there was nothing they could have done to prevent them. At the burn camp, they were able to see that the guilt felt by other parents was unwarranted, and saw that their feelings of guilt were likewise unwarranted. They learned, for example, that they may have simply been in the wrong place at the wrong time.²⁴

Help Patients See that They Have “A Rare Kind of Beauty”

Rosemarie Garland-Thomas is a leading teacher on how clinicians may most help people who have visible impairments and, more importantly, how these persons can best help themselves. She recently wrote an article that applies directly to patients who want a face transplant, entitled “What Do Unusual Faces Teach Us about the Ethics of Recognition?”²⁵ She quotes the late disability rights lawyer Harriet McBryde Johnson, whom Garland-Thomas describes as having had “an unusual appearance.” Johnson shared “social management strategies” that she found helped people move from seeing her as ugly to seeing her as “wondrous.” “It’s not that I’m ugly,” Johnson wrote; “two or three times in my life” her distinctive appearance evoked the response of wonder, an appreciation for what she called “a rare kind of beauty.”²⁶ This message is what clinicians should strive to successfully convey to patients.

On the other hand, it is possible that clinicians who do this may come across as “canned,” and so as being untrue. As noted above in another context, their good intention may serve to make patients feel worse. In these situations, it may be better to say that an appreciation of the patient’s appearance is a reality that many people, including the patient, may miss, but oth-

ers may “get,” even though the patient may not know this. Garland-Thomas uses the example of Auggie from the book *Wonder* to illustrate this.²⁷ Paul’s wife Rosa is an example of this.

Banish Ideas Based on Our Seeing Who Others Are

Sharrona Pearl suggests in her book, *Face/On: Face Transplants and the Ethics of the Other*, an approach that all of us, not just patients who want a face transplant, may find life changing.²⁸ She suggests that what we might try to do at all times is to strive to see others, not according to the ideas we form based on how they look, but on how they are actually are *inside*, if and when we can succeed in getting to know them. We constantly form ideas about people based on how they look. We can’t help this. We can, though, to some extent, learn to consciously waive away and even discard these ideas as we become consciously aware of them, and, in doing this, we may be able to “see” every person we encounter more deeply. I cannot do better than to use Pearl’s own words. She states that we must learn, as a first step, “quite literally not to see. . . .”²⁹ She says “something happens when we look,” and thus, “we must divorce the face of those we see from what in reality lies beneath.”³⁰ A second step she suggests is to allow ourselves to be “seen.” This entails, she says, acquiring a vulnerability and an openness.³¹ Some of us may find this frightening. We may not be used to trying to let others see us as we truly are. Pearl says, in sum, “anytime one takes an idea about the other to be the actual other, the ability to have contact with the other is denied.”³² “Maybe . . . we shouldn’t rely on the face as the way to begin knowing. . . .”³³ She concludes, “Straight talk: we judge the hell out of people for how they look. . . . We think how they look not just says something about who they are but is who they are. . . .”³⁴

CONCLUSION

After reviewing some medical aspects of face transplant, I have shared principally three conclusions that apply not only to these patients but to most or all patients. First, we might consider, more than we routinely do now, how painful it is for some patients to experience social death. If we come to believe that we may not have viewed their pain accurately, we may want

to allocate more resources to help enable them to re-integrate with others.

Second, there may be some patients who are a subset of this group of patients who lack access to services that could help them reduce their lived experience of social death. The needs of this subgroup may warrant prioritizing their interests more than we currently do. A possible new ground for this re-allocation would be a moral principle I referred to as “social death exceptionalism.”

Third, we may help patients by helping their loved ones to overcome distancing responses, when they seek this help from us. Loved ones may be with patients more than we are, perhaps several hours every day. The warmth and unconditional regard and acceptance of loved ones may go far to help patients feel for themselves what their loved ones have felt and continue to feel towards them.

The experiences of Paul and Rosa, the children and parents at burn camp, Garland-Thomas and Johnson, and Pearl encourage us and our patients to come to know each other more as we *actually* are.

EXPRESSION OF APPRECIATION

I would like to thank Norman Quist for pointing out numerous critical points that added nuance and balance to this article.

NOTES

1. L.L. Kimberly, M.W. McQuinn, A.L. Caplan, and N.C. Levy-Carrick, “The Ethics of Psychosocial Assessment in Vascularized Composite Allotransplantation: A Call for Transparency of Process to Support the Equitable Selection of Patients,” in this issue of *The Journal of Clinical Ethics* 30, number 4 (Winter 2019).

2. In general terms, VCA has been used to solve clinical situations that include the severe loss of bone and soft tissue that are the result of serious aesthetic, functional, and sensory deficiencies from animal attack, burns, gunshot injury, neurofibromatosis type I, and cancer ablations, among other injuries. P. Infante-Cossio et al., “Facial Transplantation: A Concise Update,” *Medicina Oral Patologia Oral y Cirugia Bucal* 18, no. 2 (2013): e263-71, p. e264.

3. I had one source of hesitation. Would I be doing this because I—to put this in its best light—was curious? If so, I would be fooling myself, rationalizing that I was pursuing this knowledge for a sound reason, when in fact this was hardly the case? This kind of curiosity is not at all uncommon. Police have been installed outside patients’ hospital rooms in the

past to protect these patients from the media. One patient had Cleveland police officers stationed outside her room until she held a press conference five months after the transplant. K.L. Coffman and M.Z. Siemionow, “Face Transplantation: Psychological Outcomes at Three-year Follow-up,” *Psychosomatics* 54 (2013): 372-8, p. 374, note 4. Optimal care for these patients, accordingly, is to tell them beforehand what to expect. Media training for patients has included rehearsals (p. 373).

4. H. Hendricks et al., “Facing a New Face: An Interpretative Phenomenological Analysis of the Experiences of a Blind Face Transplant Patient and His Partner,” *Journal of Craniofacial Surgery* 29, no. 4 (June 2018): 826-31.

5. S. Pearl, *Face/On: Face Transplants and the Ethics of the Other* (Chicago: University of Chicago Press, 2017).

6. A.H. Dorafshar et al., “Found in Space: Computer-Assisted Orthognathic Alignment of a Total Face Allograft in Six Degrees of Freedom,” *Journal of Oral and Maxillofacial Surgery* 72, no. 9 (2014): 1788-1800;

C.R. Gordon et al., “Preliminary Development of a Workstation for Craniomaxillofacial Surgical Procedures: Introducing a Computer-assisted Planning and Execution System,” *Journal of Craniofacial Surgery* 25, no. 1 (January 2014): 273-83; M. Bedeloglu et al., “Image-based Analysis of Emotional Facial Expressions in Full Face Transplants,” *Journal of Medical Systems* 42, no. 3 (January 2018): 42, doi: 10.1007/s10916-018-0895-8; C. Topçu et al., “Recovery of Facial Expressions Using Functional Electrical Stimulation after Full-Face Transplantation,” *Journal of Neuroengineering and Rehabilitation* 15, no. 1 (March 2018): 15, doi: 10.1186/s12984-018-0356-0.

7. A. Horton, “Her Body is Rejecting a Transplanted Face—And One Solution is Unthinkable,” *Washington Post*, 23 September 2019.

8. I would like to thank N. Quist for this and many other suggestions he has made that have added to this article. His suggestion of how our language embodies this bias, and at the same time further sustains it, mirrors the innumerable works that involve gender that similarly imply that males have more value than females. See, e.g., R. Tong, *Feminist Thought* (San Francisco: Westview Press, 1989), 220.

9. M.J. Green and J.R. Botkin, “‘Genetic Exceptionalism’ in Medicine: Clarifying the Differences Between Genetic and Nongenetic Tests,” *Annals of Internal Medicine* 138, no. 7 (1 April 2003): 571-5.

10. R. Huxtable and J. Woodley, “Gaining Face or Losing Face? Framing the Debate on Face Transplants,” *Bioethics* 19, no. 5-6 (2005): 505-22, pp. 506-7. See also M. Freeman and P.A. Jaoudé, “Justifying Surgery’s Last Taboo: The Ethics of Face Transplants,” *Journal of Medical Ethics* 33, no. 2 (2007): 76-81.

Joseph Heller invented the phrase “catch-22” for his anti-war novel of the same name. J. Heller, *Catch-22* (New York: Simon and Schuster, 1961).

11. This quotation is from an article by S. Lyall,

“Painting What’s Left of Faces, Sometimes What’s Behind,” *New York Times*, 3 April 2002. <https://www.nytimes.com/2002/04/03/arts/painting-what-s-left-of-faces-sometimes-what-s-behind.html?smid=nytcore-ios-share>. The article continues:

Speaking of Mr. de Lotbiniere, whose cancer is incurable, Mr. Hutchison [the surgeon at St. Bartholomew’s and the Royal London Hospital who has operated on Mr. de Lotbiniere] said: “I have removed nearly every part of his head. I’ve removed his lower jaw, his upper jaw, his eye socket, his forehead, part of his brain. It’s trite, when talking about him, to talk about courageousness. This is something more than courageous. This is a man who says: I am alive. I can do things. I am not going to let this tumor get in my way.” For his part, Mr. de Lotbiniere said he found it liberating to be painted. He is far more distressed, he said, about the loss of his faculties—he is having trouble with his remaining eye, and with his palate gone, can only talk with a special plate inside his mouth that sometimes acts up—than about the way he looks. “I thought this was wonderful—living, I mean—and I was so happy to be kept alive that it made me much more relaxed about my face,” he said. “The more people who are out there looking odd,” he said, “the easier it will be for other people to go out and join them.”

12. J.M. Sykes, “Managing the Psychological Aspects of Plastic Surgery Patients,” *Current Opinion in Otolaryngology & Head and Neck Surgery* 17, no. 4 (August 2009): 321-3, p. 322.

13. One surgeon described a rigid process for managing self-harm burn injuries, seemingly resulting from the above belief: “Our policy not to graft repeat small (deliberate self-harm) burns . . . is based on years of experience/evidence & all senior surgeons are in agreement on this matter.” L. Rai, L. Shepherd, and C.P. O’Boyle, “Quantitative and Thematic Analysis of Burns Surgeons’ Attitudes, Beliefs and Surgical Decision-Making in Self-harm Burn Injuries: The Use of a Questionnaire and Hypothetical Cases,” *Burns* 45, no. 1 (February 2019): 180-9, 185.

14. A.K. Alexander et al., “Chronically Homeless Persons’ Participation in an Advance Directive Intervention: A Cohort Study,” *Palliative Medicine* 29, no. 8 (2015): 746-55.

15. H. Hendricks et al., “Facing a New Face: An Interpretative Phenomenological Analysis of the Experiences of a Blind Face Transplant Patient and His Partner,” *Journal of Craniofacial Surgery* 29, no. 4 (June 2018): 826-31.

16. Changing Faces, a United Kingdom charity, offers anxiety management techniques, communication workshops, and educational sessions to those with facial disfigurement. *Ibid.*, 827.

17. Hendricks et al., “Facing a New Face,” see note 15 above, p. 828.

18. Pearl, *Face/On*, see note 5 above.

19. *Ibid.*

20. *Ibid.*, 829.

21. Hendricks et al., “Facing a New Face,” see note 15 above, p. 830.

22. L. Armstrong-James et al., “Using Photo-Elicitation to Explore Families’ Experiences of Burn Camp,” *Journal of Family Nursing* 25, no. 1 (February 2019): 81-108.

23. *Ibid.*, 92.

24. *Ibid.*, 94-5.

25. R. Garland-Thomson, “What Do Unusual Faces Teach Us About the Ethics of Recognition?” *AMA Journal of Ethics* 21, no. 11 (2019): E1003-8.

26. M. Johnson, “Unspeakable Conversations,” *New York Times Magazine*, 16 February 2003, <https://www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html>.

27. Garland-Thomas, “What Do Unusual Faces Teach Us?” see note 25 above; R.J. Palacio, *Wonder* (New York: Alfred A. Knopf, 2012).

28. Pearl, *Face/On*, see note 5 above.

29. Pearl refers, in this regard, to Levinas. She states, for example, “I want to think about the reflexive experience in the Levinasian moment. Put simply, in what way do I become ‘I’ when I respond to the other? It is in that question that we might begin to understand what the true potential of the face transplant or nontransplant might be for reframing how we understand identity and its relationship to the body.” *Ibid.*, 165.

30. *Ibid.*, 177.

31. *Ibid.*

32. *Ibid.*, 158.

33. *Ibid.*, 160.

34. *Ibid.*, 165.