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A Lifesaving View of Vascularized Composite Allotransplantation: Patient Experience of Social Death Before and After Face, Hand, and Larynx Transplant

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Abstract

Introduction: Most solid organ transplantation is viewed as lifesaving, whereas vascularized composite allotransplantation (VCA) has been viewed as life enhancing. This article challenges the latter and argues that "social death" evident in severe face, hand, and larynx disfigurement can be potentially treated via VCA. Social death (from a social science perspective) consists of a combination of 7 components: social isolation, loneliness, ostracism, loss of personhood, change of role and identity, harm, and disfigurement. **Methods:** In February 2016, PubMed and Google were searched for case reports of human face, hand, and larynx transplantation. Patient and team narratives were then coded for components of social death using social science and medical model criteria. **Results:** Eleven narratives were identified among 9 articles. The social science model (but not the medical model) described pretransplant social death and the resolution of social death by receiving VCA. Notably, the medical model of social death was deemed unsuitable for application to VCA. This is because case narratives consistently contradict elements of the medical model. **Conclusions:** By including social death as a patient inclusion criterion for face, hand, and larynx VCA, these transplants can be considered lifesaving. Additionally, because VCA requires lifelong immunosuppressant medication, considering VCA as a lifesaving intervention improves the technology's risk–benefit analysis. Guidance for assessing social death is provided.

Keywords

vascularized composite allotransplantation, ethics consultation, quality of life, social isolation, narrative, social death

Introduction

Vascularized composite allotransplantation (VCA) is the transplant of a structure of multiple tissue types (skin, bone, muscle, nerves, and blood vessels) combined as 1 anatomical unit. Examples include hand, leg, penis, and the face. Worldwide, over 100 hand/upper extremity transplants (1) and 31 face transplants (2) have been performed, and successful programs in penis (3) and uterus transplantation (4) also exist. Compared to lifesaving solid organ transplantation, all forms of VCA have been considered life enhancing. Vascularized composite allotransplantation (like solid organ transplant) requires lifelong immunosuppressant medication which is known to have risks such as infection, cancer, diabetes, hypertension, and renal failure (5), and these potential consequences have caused some to deem VCA too risky in light of the potential benefit (6). Unfavorable risk–benefit calculations for nonlifesaving treatment also factor into decisions by health systems/insurance companies to deny funding for VCA (6–8).

The indications for VCA are both medical and psychosocial because VCA allografts are personal social organs (often visible). Furthermore, VCA is not considered the first-line therapy for limb/structure loss. Vascularized composite allotransplantation is only considered after other interventions are deemed unsuccessful or futile (eg, prosthetics). Patient selection is a careful, methodical process involving many team members including plastic surgeons, vascular surgeons, physical and occupational therapists, and a social worker, psychologist/psychiatrist, immunologist, and clinical ethicist (9). This article focuses on the patient experience

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Table 1. Social Science Model and Medical Model of Social Death.

Medical Model (8 Components)	Social Science Model (7 Components)
[a]Restriction of the physical territory of life (eg, staying home)	[a]Social isolation
Irreversibility of the "death" state	Loneliness
Abolition of linear time (stuck in rituals and perpetuation of the present with lack of projection about the future)	Ostracism
Modified conception of the body in terms of its need for health care (eg, refusal of treatment)	Personhood
Transformed tolerance to pain (eg, loss of expression about pain)	Role and identity
Degradation of personal hygiene	Harm
Athymic state (affective indifference with excessive guilt)	[b]Disfigurement
Biological signs such as serotonergic disorders, secondary amenorrhoea, and thermostatic anomalies	

[a]Overlapping criterion, medical and social science model of social death.
[b]Presence of a physical disfigurement (eg, burn injury and amputation).

of social death and its potential use as an inclusion criterion for face, hand, and larynx transplants.

Social death as defined by social scientists (social science model; Table 1) is a multifaceted concept comprised of ostracism (ignored and excluded from others by others or self; 10,11), social isolation and loneliness (12), and loss of personhood and a worthwhile life (13). Closely linked to loss of personhood and a life worth living is alteration in one's identity (14–16) and life role. Social death is not just psychological, but it is also physical because the ostracism component has been shown to cause physical pain (11). After extensively reviewing the existing literature on social death, Králová (17) has argued that social death has 3 foundational elements: loss of social identity, loss of social connectedness, and losses associated with disintegration of the body. Indeed, all 7 components of social death presented in Table 1 link to Králová's theory.

Social death defined by physicians (medical model) has 8 "clinical and biological criteria" (18; Table 1). These criteria were created in 2015 based on the experience of a physician who had worked at a large homeless shelter in Paris (18): irreversibility of the "death" state; abolition of linear time (stuck in rituals and perpetuation of the present with the lack of projection about the future); restriction of the physical territory of life (eg, staying home); modified conception of the body in terms of its need for health care (eg, refusal of treatment); transformed tolerance to pain (eg, loss of expression about pain); degradation of personal hygiene; athymic state (affective indifference with excessive guilt); biological signs such as serotonergic disorders, secondary amenorrhoea, and thermostatic anomalies.

Social death has been linked to increased mortality (biological death), including increased suicidal ideation and suicide attempts (11,12,19). Additional to homeless people, social death has been documented in many groups including the terminally ill (13), those with dementia (13,20), patients with coma (13), patients with facial disfigurement (21,22), victims of genocide (23), patients with severe burns (17,24), as well those with HIV/AIDS (25). This is the first analysis of social death in the field of VCA. Furthermore, this analysis provides evidence that refutes 4 of 8 criteria of the medical model of social death (18).

Methods

In February 2016, PubMed was searched for all articles reporting human face, hand, and larynx transplantation. Google was also searched for media reports of human face, hand, and larynx transplants. Only articles in English containing patient or team narratives of case reports were included for analysis. The narratives were then coded for the 7 components of social death (social science model): social isolation, loneliness, ostracism, loss of personhood, change in role and identity, harm, and disfigurement. The narratives were also coded using the medical model (18); however, because medical charts were not available for the patients from each case report, it was impossible to code the narratives with regard to 3 of 8 criteria (degradation of personal hygiene, athymic state, and biological signs). Also, a word list was manually created from the narratives, selecting for terms correlating to the themes within social death. Phrases were included to retain context. Additionally, a concept map (available online as a Supplemental file) was created as a tool to assist coding analysis. Results of the narrative analysis, word list, and concept map were used to help shape the social death assessment queries (Table 2).

Results

Nine articles were retrieved, and 11 narratives were identified within these articles. Nine narratives of patient experience were reported by VCA team members; 2 narratives were directly reported by VCA patients. In all narratives, it was evident that patient disfigurement was linked to the social science model of social death. Four of 5 assessed criteria within the medical model of social death were refuted: irreversibility of the "death" state, abolition of linear time (perpetuation of the present with the lack of projection about the future), modified conception of the body in terms of its need for health care, and transformed tolerance to pain (eg, loss of expression about pain). Within the medical model, restriction of the physical territory was evident in 8 of 11 narratives.

Social Death and Facial Transplantation

The face is a social organ as it communicates words and emotions. It also facilitates body functions, such as eating, drinking, blinking, speech, vision, and hearing. The face also feels and it exudes identity. Severe facial disfigurement can

Table 2. Assessment of Social Death Using the Social Science Model of Social Death.

Component	Word List (From Narratives)	Assessment Queries
Social isolation	Walking in street (F1) Meeting people (F1) Party (F1) Returned (F4) Enhanced social capacity (F4) Social life easier (F5) Crowd (F5) Social activities (F5) Social circle (H1) More attractive socially (H1) Social relationships (H2) Other people (H3) Family (H4)	Does patient live alone? Does patient have few social network ties? Does patient have infrequent social contact? Is the patient engaging in social withdrawal?
Loneliness	Anonymous (F5) Crowd (F5) Other people (H3)	Does patient experience loneliness? How often? How does he/she attempt to resolve it?
Ostracism	Everybody else (F2) Fully reintegrated (F4) Into the community (F4) Provoking aggressive reactions (F5) Perceived by other people (H1) Social approval (H3) Openness (H3)	Does patient feel ignored, excluded or alienated by others? Cautious about interaction with others? Does the patient self-ostracize?
Personhood	Esthetic and functional results (F1) Reduced concern about appearance (F5) Monster (F5) Anonymous (F5) More attractive physically (H1) Equal member of society (H1) Body image (H2) Body's looks (H3) Reconstructed body (H3) More attractive (H3) Manlier (H3) Results (L1)	Does patient feel less of a person/less human due to his/her disfigurement?
Role and identity	Full-time job (F5) Shopping (F5) Employed (F5) Accounting agent (F5) Needed (H1) Family (H1) Workplace (H1) Regain his self-confidence (H1)(H2)(H3) Self-esteem (H3)(H4) Significant restoration of his Social position (H1) Full-time employment (H1) Useful to society (H1) Husband (H1)(H3) Father (H1)(H3) Man (H2)(H3) Push a stroller (H3) Drive a car (H3) Make a hole (H3) Repair (H3) Looking after his children (H4)	Does the patient feel empty or worthless? Does the patient feel that he/she has lost their value to others (family, community, and job)? Has his/her sense of purpose changed?

(continued)

Table 2. (continued)

Component	Word List (From Narratives)	Assessment Queries
	Driving (H4)	
	Organizing (H4)	
	Social status improved (H4)	
	Professional role (H4)	
	Professional life (H4)	
Harm	Very satisfied (F1)	Does the patient have suicidal thoughts or has there been a suicide attempt? Is he/she depressed? Is he/she abusing food, drugs, alcohol, or other substances?
	New life (F3)	
	Peace (F5)	
	Quality of life (F5)(L1)	
	Enormous satisfaction (H3)	
	Great delight (H4)	
	Emotions (H4)	
	Joy (H4)	
	Inner peace (H4)	
	Restored my life (L2)	
	Positive changes (H4)	
	Beneficial influence (H4)	
	Very pleased (L1)	
	Improved immeasurably (L1)	
Disfigurement	Face (F2)	How much does the patient's disfigurement play a role[a] in the above 6 components?
	Limb (H1)(H2)	
	Hand (H3)	
	Since (F2)	
	Gained (F3)	
	Easier (F5)	
	Dear improvement (F5)	
	Better (H1)	
	Radical change (H1)	
	Successfully (H1)	
	Fully incorporated (H2)	
	Regaining (H2)	
	Again (H2)	
	Fulfils better (H3)	
	Higher (H3)	

[a]The disfigurement's functional/physical as well as psychological/existential impact.

contribute to social death (21,22), but facial transplant can potentially be a treatment as shown below:

> F1: "At present, the patient says she is not afraid of walking in the street or meeting people at a party, and she is very satisfied with the aesthetic and functional results." VCA team reporting on outcome of female patient, 10 months postface transplant (26).
>
> F2: "Since the day of the operation, I have a face like everybody else." Female patient, 1 year postface transplant (27).
>
> F3: "(The patient) gained a 'new' life as she started to interact again socially. . . . " VCA team reporting on outcome of female patient, 5 years postface transplant (28).

The 3 texts above describe the same patient with long-term follow-up. The use of the word "again" in the third narrative indicates that prior to facial transplantation, the patient was socially isolated. In the second narrative, the word "since" implies that prior to the surgery, her face was not like everyone else's and indeed it was not, as it was severely disfigured from dog mauling (26). Collectively, these 3 narratives involve the following components of the social science model of social death: social isolation, role and identity, ostracism, and personhood.

> F4: "The patient returned to his living facility within 5 weeks after the operation and became fully reintegrated into the community with enhanced social capacity." VCA team reporting on outcome of male patient, 1 year postface transplant (29).

In the text above, the use of the word "reintegrated" indicates that prior to facial transplantation (following a high-voltage electrical burn), the patient was segregated from his community, and this segregation links to isolation and ostracism within the social science model of social death. Facial transplant facilitated both reentry to his community and "enhanced social capacity."

F5: "... the transplant has reduced his concern about his appearance, which has made having a social life easier for him. He began a full-time job 13 months after transplantation. Before surgery, the patient felt he was considered a 'monster,' whereas he now feels like 'an anonymous person in the crowd.' Daily social activities are easier. For example, the patient can now go shopping in peace, without provoking aggressive reactions. He is now employed as an accounting agent. There was thus a dear improvement in the patient's quality of life..." VCA team reporting on outcome of male patient, 1 year postface transplant (30).

Referring to the social science model of social death, the text above indicates that prior to facial transplantation, many social constructs of this patient's life were impacted by disfigurement (due to severe neurofibromatosis). Specifically, his personhood was affected in that he felt he was considered a "monster," and his role and social interactions were impacted through ostracism. Facial transplantation "made having a social life easier," enabled him to gain employment, and provided him with a face that allowed assimilation rather than exclusion.

Overall, the medical model of social death did not align well with these face transplantation cases. Specifically, for these patients, their social death was reversible (not irreversible), they were motivated to change their situation and aim for a new future, and they were motivated to seek medical treatment that required their adherence (otherwise they would not have been placed on the transplant list). In accordance with the medical model of social death, patients did evidence restriction of their physical territory prior to VCA.

Social Death and Hand Transplantation

The hands contain fingerprints, a form of personal identity. Hands are also used in communication (gesturing), work (moving objects and manual creations), feeding, dressing, grooming, touching, and feeling. The potential for VCA to treat the social death of patients with severe limb disfigurement or amputation can be identified in the following posttransplant chronicles:

H1: "Thanks to the transplantation, he can use it better, thus feeling needed in his family, workplace, and social circle. The limb transplant helped the patient regain his self-confidence. He feels more attractive physically and socially. In this case, transplantation benefits also include a significant restoration of his social position. Full-time employment gives him the feeling of being useful to society. The recipient also successfully performs the roles of husband and father. The patient sees a radical change in the way he is perceived by other people. He feels an equal member of society." VCA team reporting on outcome of male patient, 6 years posthand transplant (31).

The text above contains many examples of how hand transplantation facilitated treating this patient's social death (viewed via the social science model). Specifically, prior to transplant, the patient lost his hand in an industrial accident. In the posttransplant setting, use of the words "regain," "restoration," and "being useful to society" link to concepts of personhood, role and identity, and social isolation, as examples. Feeling "needed" and an "equal member of society" can potentially mediate issues of ostracism.

H2: "The patient fully incorporated the transplanted limb into his body image, regaining self-confidence in social relationships. He feels 'as a man again'..." VCA team reporting on outcome of male patient, 41 months posthand transplant (32).

The use of the word "regaining" in the above text indicates that the patient's social relationships were marred by the loss of his hand (industrial accident). Posttransplant, the regaining of self-confidence in social relationships can mitigate matters of isolation and loneliness. Feeling "as a man again" is clearly linked to role and identity, and this too can have links to other components of social science model of social death.

H3: "He clearly sees social approval for his body's looks. Openness to other people stems from regained self-confidence and higher self-esteem. He perceives his reconstructed body as more attractive and manlier. He believes that he fulfills better his role of a husband and father. The fact that with his grafted hand, he can push a stroller with a child, drive a car with a manual transmission, make a hole in a wall with a drill or repair a computer gives him enormous satisfaction with being a man." VCA team reporting on outcome of male patient, 5 years posthand transplant (31).

In the text above, posttransplant "openness to other people" can be linked to components of the social science model of social death, such as social isolation, loneliness, and role and identity. Additionally, hand transplant (following a childhood farming accident) restored physical functioning so that he could perform the social roles of husband and father.

H4: "He takes a great delight in looking after his children, and particularly in using the grafted hands to perform such everyday tasks as cooking a meal for the children, driving them to school or organizing special activities. The patient's social status improved by his return to his professional role. Positive changes in the patient's family and professional life have had a beneficial influence on his self-esteem. The emotions that dominate the recipient's posttransplantation life are joy and inner peace." VCA team reporting on outcome of male patient, 3 years postbilateral hand transplant (31).

In the above text, the fact that the patient's "social status improved by his return to his professional role" is linked to the social death concepts of role and identity (social science model). Additionally, the fact that the patient has "joy and inner peace" posttransplant (cause of original injury unknown) indicates that hand transplant can potentially mitigate harm, ostracism, and loneliness (social science model of social death).

Overall, the medical model of social death did not align well with these hand transplantation cases. Specifically, for these patients, their social death was reversible (not irreversible), they were motivated to change their situation and aim for a new future, and they were motivated to seek medical treatment that required their adherence (otherwise they would not have been placed on the transplant list). In accordance with the medical model of social death, patients did evidence restriction of their physical territory prior to VCA.

Social Death and Larynx Transplant

With regard to potential larynx transplant candidates, the lack of a voice can mean lack of effective communication as well as identity, and in the field of speech pathology, these harms are termed "social penalties"(33). To date, layrnx transplantation has been performed 3 times and shown to restore not only voice but also smell, taste, and the enjoyment of eating (34). In contrast, the use of an external electrolarynx device provides only a robotic, mechanical voice (35). A male who received the first successful larynx transplant in 1998 but experienced explant due to graft failure 14 years later is hopeful for a retransplant in the future (36). This patient's aphonia occurred following a throat injury in a motor vehicle accident.

> L1: "[The patient] was very pleased with the results and reported that his quality of life had improved 'immeasurably.' Unemployed before the transplantation, he has since become a motivational speaker." VCA team reporting on outcome of male patient, 40 months postlarynx transplant (34).
>
> L2: "This operation has restored my life." Female patient, 3 months postlarynx transplant, prior aphonia due to surgical complication (37).

The statements above show the potential for voice restoration (via larynx transplant) to impact components of the social science model of social death, such as role and identity as well as ostracism and isolation. To take on the role of a motivational speaker is the antithesis of social withdrawal. Overall, the medical model of social death did not align well with these larynx transplantation cases. Specifically, for these patients, their social death was reversible (not irreversible); they were motivated to change their situation and aim for a new future; and they were motivated to seek medical treatment that required their adherence (otherwise they would not have been placed on the transplant list). In accordance with the medical model of social death, there was evidence restriction of physical territory prior to VCA in 1 patient (shifting from unemployed to business traveler).

Discussion

Clinicians are ethically obligated to provide whole-person care and, in doing so, must consider not only biological death but also that social death can occur when patients are isolated, depressed, and/or unable to work as a result of their disfigurement. Social death is a larger construct than the discrete psychological constructs of anxiety and body identity disorders (examples with discrete diagnostic criteria). These latter matters can be present in patients seeking VCA; however, they might not evidence social death. In the social science model of social death, at least one of the following is present: social isolation, loneliness, ostracism, altered personhood, altered role and identity, and personal harm. Additionally, there is a link between the patient's disfigurement and one or more of the other components (Table 1). Notably, the medical model of social death is not suitable for application to VCA. This is because case narratives consistently contradict 3 elements of the medical model. Additionally, a fourth element (pain tolerance or loss of expression about pain) is also contradicted because it is known that one of the reasons for seeking VCA is complaints about pain (38,39).

The word list methodology used in this project (Table 2) facilitated creation of social death assessment questions. These and related questions should guide the assessment process during direct patient interview (rather than curbside consults). Similar to their role on solid organ transplant teams (40,41), clinical ethicists commonly assist VCA teams with various aspects of the VCA program, including the assessment of recipient candidates. The ethicist does not work in isolation of the team psychologist, psychiatrist or social worker; however, the ethics assessment is additional to the psychosocial assessment performed by social workers. Using the common four-box method of clinical ethics consultation (Table 3; 42), the assessment of social death is consistent with the activities of box 2 (quality of life assessment). During this component of the clinical ethics consultation, the ethicist focuses on understanding the patient's perception of his/her quality of life, as well as the clinical potential for improving quality of life through VCA. This said, ethicists are well-placed to assess social death using the social science model (Table 1) acknowledging there is currently no social death score or calculation. Findings should be charted in the ethics consult note (43) and include specific referrals to the team social worker and psychologist for follow up as appropriate. If the patient is identified to be at risk of self-harm, the ethicist should follow the facility's standard operating procedure for managing this risk. Discussion of the patient assessment resulting in a multidisciplinary team meeting is advantageous as it fosters contextual reflection and consideration from various team specialties. Also, the inclusion of social death discussions in these multidisciplinary settings fosters a place for social death as a patient

Table 3. Four-Box Method of Clinical Ethics Consultation.[a]

1. Medical indications: The clinical features of the case including urgency, acute versus chronic, inpatient versus outpatient, and adult versus child; what treatments offer benefit? Which are futile?	3. Patient preferences: The patient's wishes about treatment (consent or refusal) as expressed verbally or through an advance directive and requires assessment of patient's decisional capacity. Includes assessment for ambivalence and motivation. If there is a surrogate decision-maker, does he/she know the patient's values?
2. Quality of life: The patient's perspective of his/her quality of life and the potential of improving quality of life through medical, surgical, or other interventions	4. Contextual features of case: Nonclinical variables that potentially impact the case such as the patient's religious values, financial status, relationship status, occupation, habitation and immigration status, conflict of interest, and so on are analyzed reflecting on Box 1, 2, and 3

[a]Adapted from Jonsen AR et al (42).

variable and thus gives everyone on the team (no matter their specialty) the opportunity to assess and manage social death in their VCA patients.

Could another VCA team member such as the social worker, psychologist, or psychiatrist perform the social death assessment instead of the clinical ethicist? The concepts of quality of life and personhood sit in the domain of clinical ethics (42), thus social death assessment is suited for inclusion with the clinical ethics consultation. If a VCA team lacks a clinical ethicist (on staff or as an ad hoc consultant), the assessment could potentially be performed by a psychologist or psychiatrist who has experience in identifying, exploring, and resolving dilemmas involving these ethics constructs as they also cross the social science domain. As noted above (42), the scope of ethics consultation extends beyond exploring social death, thus access to a clinical ethicist is valuable. Additionally, because the medical model of social death is not suited for VCA, there seems no necessity to restrict the performance of social death assessments to psychiatrists (or other physicians).

Social death assessment is applicable for both adult and pediatric patients. To date, there have been only 4 cases of pediatric VCA, 1 lower limb transplant (44) and 3 upper limb transplants(45–47), thus the pediatric data set is very limited. For children and teens, their experiences of social isolation, loneliness, ostracism, personhood, role, and identity will likely be different to those of adults; however, their experiences are still valid to the concept of social death.

The physical pain of social death (11) and its risk of increased biological mortality (11,12,19) are significant matters. Although prosthetics exist for many types of disfigurements (eg, facial masks and wigs; artificial limbs), they are often not a suitable treatment for social death, and patients continue to seek other remedies, including VCA. The reasons for prosthetic failure are many including poor function, complications, and the inability to use them all the time. And while the role of psychiatric medication, talk therapy, and support groups cannot be underestimated, for some patients, physical restoration is still desired.

By including the social science model of social death as an inclusion criterion for face, hand, and larynx transplant, these VCAs can be considered potentially lifesaving. Specifically, "lifesaving" can be viewed in 2 ways. Indeed, others have already argued that hand transplant can be considered potentially lifesaving due to the increased risk of suicide in amputees (48). This said, saving biological life by reducing suicide is a form of lifesaving. However, another view of lifesaving is posed; that is, "curing" social death can restore life in the psychological/existential sense. Viewing well-being as a combination of the physical and psychological/existential, social death is "the antithesis of well-being" (17) and curing social death can help restore well-being. Furthermore, in light of the need for lifelong immunosuppression, the inclusion of social death in the VCA risk–benefit analysis alters the ratio more favorably. This improved risk–benefit ratio also promotes the potential for positive funding decisions by health systems/insurance companies (6–8). It must be noted, however, that this lifesaving concept of VCA runs afoul of the medical model of social death because the medical model views social death as irreversible (and ultimately leading to clinical death; 18).

What if a severely disfigured person seeks VCA but does not evidence social death? In the absence of social death, the VCA team must consider the patient's future risk of social death and if this risk is significant, VCA should be considered an option (not withstanding other medical and psychosocial inclusion criteria). However, even those not evidencing social death, nor a risk of future social death can be VCA candidates as long as they have the capacity to benefit from what VCA potentially offers (eg, functional restoration). It must be noted that the medical model of social death would not include VCA candidates because these patients, to be eligible for VCA, must have a positive projection about their future and the motivation to seek transplantation with an attitude of therapeutic compliance. In the medical model of social death, these attributes are not observed.

What if assessment identifies social death but the patient is deemed unsuitable for VCA? Vascularized composite allotransplantation should not be viewed as the only treatment for social death, and in fact, VCA itself can be unsuccessful necessitating many revisions or even graft explant. Additionally, those experiencing components of social death that render them poor candidates for VCA transplant (eg, active drug/alcohol abuse or dependence, uncontrolled eating disorders, uncontrolled mental illness, and poor self-care) could find social death as a transplant exclusion criterion. The findings from the social death assessment note should engage the social worker and psychologist to help devise an alternate treatment strategy for non-VCA

candidates. This strategy could potentially include focused psychotherapy (all patients) and optimized prosthetics (face, limb, and larynx).

A limitation of the presented work is that the patient chronicles that were analyzed were not derived from formal social death assessments but rather general pretransplant and posttransplant case reports. Furthermore, some text is the words of the patients themselves, whereas others are the words of the VCA team. Nonetheless, this work is a novel first step in analyzing the concept of social death in the field of VCA.

Assessing social death in the setting of transplantation is an emerging field, and the work presented represents first steps toward understanding social death in that setting. These first steps also help pave future paths toward larger and more complex studies (eg, prospective research with pretransplant and posttransplant in-person patient interviews), with the ultimate aim of creating a formal social death scoring tool. The goal is to use the tool to quantify social death, measuring it along a spectrum according to how the 7 components interplay. With regard to biological death, humans are either alive, near death, or dead. Similarly, with social death, humans are either socially alive, nearing social death, or evidencing social death. Upon validation, the scoring tool will define a threshold for the determination of social death. Such a tool might also be useful to assess other patients (eg, those with terminal illness or mental health issues, such as social anxiety disorder or depression).

SUMMARY BOX

What is already known on this subject:

- Most solid-organ transplantation is viewed as lifesaving whereas vascularized composite allotransplantation (VCA) has been viewed as life enhancing.
- Unfavorable risk–benefit calculations for nonlifesaving treatment factor into decisions by health systems/insurance companies to deny funding for VCA.

What this study adds:

- The social science model of social death described pretransplant social death and the resolution of social death by receiving VCA.
- The medical model of social death is unsuitable for application to VCA because case narratives consistently contradict elements of the medical model.
- By including social death as a patient inclusion criterion for face, hand, and larynx VCA, these transplants can be considered lifesaving.
- Guidance for assessing social death is provided.

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Supplemental Material

Supplementary material for this article is available online.

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