

**CASE AND COMMENTARY**

**Should a Caregiver's QoL Be Considered in Decisions About Whether a Patient Has an Experimental Double-Hand Transplant?**

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**Abstract**

A goal of hand and upper extremity transplantation is to return motor and sensory function to an amputee. Given the integral roles of one's hands in activities of daily living and social interaction, however, restoring psychosocial well-being should also be a priority. Based on the authors' experience, double-hand transplantation success depends significantly on strong social support, physical rehabilitation, medication adherence, and social integration. Because caregiving is demanding, tasks should be distributed among members of a patient's family and social network. This article analyzes how to respond to an overwhelmed caregiver by drawing on solid organ transplant literature about caregiver fatigue.

**Case**

C is a quadrilateral amputee who lives with her partner, N. After 2 years of working with prosthetics and outfitting their apartment with assistive devices, N and C have a life together they enjoy.

When C is offered an opportunity to be evaluated for an experimental double-hand transplant by Dr PT, her long-time physical therapist (who is working with a newly formed research team at their hospital), N struggles with the idea of a radical change in her own and C's living situation. Despite N's devotion to C, she is worried about how she would manage additional caretaking responsibilities if an experimental surgery does not turn out well for C. N agrees with C, however, that having C be evaluated would give them an opportunity to consider possible benefits and risks.

During C's evaluation to consider whether she meets the criteria for enrolling in the double-hand transplant research protocol, N tries to gain information about possible effects that a double-hand transplant would have on her own quality of life without seeming self-absorbed or unsupportive of C's enthusiasm about the protocol. N asks, "What will C's recovery process be like?"

Dr B, the study's principal investigator, responds, "I wish I could tell you it's going to be quick and easy. But as you can probably imagine, it will likely be neither. In above-elbow amputees, like C, we expect nerve regeneration to take 1½ to 2 years.<sup>1</sup> Nerves grow at a rate of about a millimeter per day. So, in the first year after the transplant surgery, C will need help with almost all aspects of self-care and rehabilitative therapy."

N struggles to keep her expression neutral and optimistic, but she is distressed by this information. The transplant team's physical therapist, Dr PT, who is helping to facilitate the conversation, notices N's distress as the team concludes the evaluation.

Dr PT remarks to Dr B later, "N was clearly upset and seemed overwhelmed, and who wouldn't be. I wish we had brought N into the conversation more about whether hand transplant is the right choice for C and for them as a couple. Highly involved partners and family members provide critical support to our study participants' abilities to adhere to postsurgical care recommendations. They'll both need a lot of support in the follow-up years if C participates in our study. It seems we should somehow be incorporating the caregiver more in our evaluations. How should we do that?"

### Commentary

Hand and upper extremity transplantation restores form and function to bilateral amputees,<sup>1</sup> with recipients experiencing good motor and sensory outcomes 6 or more years posttransplant.<sup>2,3</sup> It persists as the most common type of vascularized composite allotransplant. More than 100 such transplants had been reported worldwide by 2018.<sup>4</sup> Although patient survivability surpasses 95% at 10 years,<sup>5</sup> unlike solid organ transplantation, this procedure's primary aim is not to extend life in relatively ill patients but to improve quality of life in relatively healthy patients.<sup>6,7,8,9,10</sup> For both kinds of transplants, life-long immunosuppression, which is necessary to prevent graft rejection or loss, increases the risk of developing oncologic malignancy and metabolic disorders like diabetes mellitus and heightens susceptibility to infections.<sup>11</sup> Nevertheless, acute allograft rejection is nearly assured within the first year in 4 of 5 hand transplant recipients, although it is reversible when treated promptly.<sup>12</sup> Although some candidates might be informed of these statistics during preoperative consultation and informed consent processes,<sup>13</sup> evidence is limited of patients' and caregivers' understanding of, expectations for, and experiences of surgery and its postoperative demands.

Efforts are being made to study hand and upper extremity transplant recipients and caregivers outside of laboratory settings.<sup>14</sup> Herrington et al explored the [narratives](#) of caregivers who often felt burdened by demands of providing care,<sup>15</sup> despite their being crucial for long-term patient well-being and allograft survival.<sup>16</sup> Caregiving imposes physical and psychosocial demands on caregivers that affect their health and well-being sufficiently to impact the care they provide.<sup>17,18</sup> This caregiver

burden is amplified in nonprofessional caregivers who are often untrained and unprepared to perform skilled medical tasks.<sup>19</sup> Given these potential burdens, should finding a balance between a patient's need and desire for bilateral hand transplantation and a nonprofessional caregiver's well-being become the responsibility of the treatment team?

With little written about caregivers in hand transplantation, our aim as members of a reconstructive transplant team is to reflect on that question and share insights from our 10 years of experience. In this case commentary, we elucidate the unique role of nonprofessional caregivers, such as N, in hand transplantation. We then highlight positive behavioral characteristics of potential caregivers and concerning red flags. Finally, we provide suggestions to improve the assessment of caregiver burden and its prevention.

### **Understanding the Caregiver Role**

In this case, N has limited experience in providing medical care as she is not a professional caregiver, such as a physician or a visiting nurse. Yet after 2 years of working with prosthetics and assistive devices, N has managed to balance her caregiving and personal responsibilities to develop an enjoyable life with C. Now that C is considering bilateral hand transplantation to meet her individual treatment goals, which for many candidates involve complex considerations and decisions,<sup>20</sup> N realizes her role as a nonprofessional caregiver could change.

Nonprofessional caregiving for prosthetic users and hand transplant recipients differs in several respects. If needed at all, nonprofessional caregiving for prosthetic users is of much shorter duration than the 1½ to 2 years required for bilateral hand transplant,<sup>1</sup> and it presents caregivers with different physical and financial responsibilities than would a bilateral hand transplant.<sup>21</sup> In addition, hand transplant patients' morbidity, mortality, and degree of social reintegration are dependent on the nonprofessional caregivers' long-term commitment and social support.<sup>16</sup>

After learning the risks of the surgery, that roughly 17% of unilateral and bilateral hand transplant recipients suffer graft loss,<sup>22</sup> and that additional caretaking responsibilities would be required if everything were to go well, N realizes the impact that the transplant could have on her well-being. Nerve regeneration might prolong the need for aiding C with activities of daily living.<sup>23,24</sup> This possibility, combined with the strenuous rehabilitative regimen,<sup>25</sup> would hinder N's ability to participate in social activities—potentially straining her relationship with C.<sup>26</sup> Given these burdens, consultation must consider the needs of nonprofessional caregivers like N to be an extension of the patient's needs via their social relationship.

### **Positive Caregiver Characteristics and Red Flags**

No quantifiable or standardized assessment of caregivers exists for hand transplantation. Instead, our treatment team discusses whether caregivers can

fulfill the obligations of their role, including assisting in medical management that frequently changes after tailoring the immunosuppression regimen, performing wound care and occupational therapy at home, providing psychosocial support and a second set of ears during hospital visits, monitoring the health of the allograft, and assisting with activities of daily living such as transfers, bathing, cooking, cleaning, and hygiene. These tasks might overwhelm a nonprofessional caregiver who has other life and work responsibilities. However, the burden of these tasks can be mitigated by sharing caregiving responsibilities among a group of nonprofessional caregivers working as a caregiving team.<sup>27</sup>

Based on our experience, positive characteristics of nonprofessional caregivers include

- Willingness to be present, to learn, and to help the hand transplant recipient.
- Dutifully executing the tasks listed above.
- Demonstrating the stability and resilience needed to focus on the patient's needs.
- Clearly expressing that one's obligation is to the patient, not the patient's team of professional caregivers (ie, the transplant team).
- Honesty or warranted trust in the treatment team.

A caregiver of one of our patients demonstrated these characteristics by taking a leave of absence from work to provide care for her spouse. This unfaltering support continued throughout the first 2 years posttransplant, a time when poor caregiver support has been shown to increase medical nonadherence in cardiothoracic transplantation.<sup>28</sup> Once the rehabilitative routine eased up, the caregiver returned to work and integrated her new caregiving responsibilities into her daily routine, remaining an excellent caregiver to her spouse. The strong social relationship between patient and caregiver contributed to the overall success of our case as well as to the couple's alacrity in forming a trusting relationship with our treatment team; a trusting patient-clinician relationship has been linked with improved pain control, functionality, and mental health for knee replacement recipients.<sup>29</sup> In N's case, Dr PT recognizes that early consideration of the patient-caregiver unit would build the rapport needed to ascertain the appropriateness of hand transplantation for both N and C.

In contrast, proceeding with transplantation when the behavior of the patient's nonprofessional caregiver puts up red flags could jeopardize the postoperative health of the recipient and the allograft. From our experience, concerning red flags include

- Impeding therapy or consultation.
- Financial impoverishment to a degree that would hinder postoperative care.

- Living geographically distant from the recipient without plans to relocate after transplant.
- A general lack of preparedness.
- Dishonesty or an unwarranted distrust of the treatment team.

These red flags factored into a decision at our institution to deny candidacy, despite the patient's meeting medical necessity guidelines for transplantation.<sup>30</sup> The couple showed general lack of preparedness for temporarily relocating and maintaining financial stability for themselves and their young children. This behavior conflicted with our duty to treat. Related to the lack of preparedness, the couple's expectations of financial security from medical celebrity after hand transplantation were unfounded. Additionally, the caregiver would seldom accompany her partner to consults, but, when present, the caregiver perseverated on the inability to find a donor—a not uncommon happening<sup>31</sup>—and often became argumentative. Differences between the nonprofessional caregiver and the treatment teams impeded the development of trusting relationships, which led to our institution's declining this patient's candidacy for transplant. If nonprofessional caregivers like N seem unwilling to speak up, treatment teams should consider scheduling appointments specifically with those caregivers to better assess their ability to be a supportive team player. Transplant teams that do not secure reliable support for patients like C risk unsafe hand transplantation.

Our method of assessment is not perfect. One particular case at our institution blindsided the treatment team the day of transplantation. The patient and caregiver came to appointments together over months of pretransplant consultations, despite living far away, as many reconstructive transplant patients do.<sup>32</sup> The nonprofessional caregiver demonstrated willingness to provide supportive care and showed no indication of an inability to cope with the burdens of transplantation. On the day of the surgery, however, the caregiver arrived intoxicated and incoherent. After 3 days of similar behavior, it became evident that the caregiver would be unable to fulfill the obligations demanded of the role, which speaks to the difficulty of ascertaining coping styles in caregivers.<sup>33</sup> Another member of the patient's nonprofessional caregiving team was contacted and came immediately to meet with the patient and treatment team, eager to learn what would be helpful in assuming the role of primary caregiver. Fortunately for this patient, the caregiving transition did not negatively impact the postoperative course.

### **Significance of Caregiver Burden and Suggestions for Prevention**

Given nonprofessional caregivers' significant impact on graft survival and overall patient well-being and their crucial rehabilitative role outside of the hospital,<sup>16</sup> a [moral obligation](#) exists to include caregivers and their well-being in considerations of a patient's candidacy for hand and upper extremity transplantation. It would disrespect the transplant recipient's autonomous desire to undergo a successful rehabilitation if the treatment team neglected to provide forward-thinking

guidance to the nonprofessional caregiving team. Furthermore, it could undermine the recipient's attempts to regain personal independence and self-identity if caregiver burden is not addressed. Besides being a sound choice, caring for the burdened caregiver is upheld by our professional medical ethos.<sup>34</sup> As such, understanding the ability of caregivers to appraise their experiences, to access resources or support, and to care for themselves aids treatment teams in recognizing and affirming their vital role in supporting transplant recipients' physical, psychological, social, and spiritual well-being.<sup>35</sup>

Specific assessment for, and early detection of, caregiver burden hinges on serial evaluations with members of the treatment team and on implementation of evidence-based interventions.<sup>36</sup> Implementing the following recommendations would help determine an individual's ability to be a reliable nonprofessional caregiver to a hand transplant recipient.

1. *Completion of a social contract.* In lieu of a medicolegal informed consent form, a social contract could be completed by nonprofessional caregivers. Such a document is not legally binding but articulates nonprofessional caregivers' social bond with and obligations to their friend or loved one. A failure to complete the form would be a red flag to the transplant team signaling the individual's unwillingness to take on caregiver responsibilities.
2. *Expanding in-depth psychosocial assessments.* [Psychosocial assessments](#) could be expanded to include nonprofessional caregivers in preoperative consultation, with a particular focus on coping abilities. Implementing such an in-depth psychosocial evaluation might improve our approach and could assist in determining the coping abilities of nonprofessional caregivers like N.
3. *Development and adoption of a hand transplant-specific tool.* Similar to the Family Caregiver Activation in Transitions tool,<sup>37</sup> a hand-transplant-specific tool could guide interventions intended to enhance caregiver preparation and confidence during care transitions. For caregivers like N, this tool could highlight areas for which another nonprofessional caregiver or the transplant team could provide additional support.

### **Successful Nonprofessional Caregiving**

Anecdotal evidence from our experience is consistent with the literature and suggests that the success of hand and upper extremity transplantation depends significantly on strong social support from a nonprofessional caregiving team that assists with physical rehabilitation, medication adherence, and social integration. In consulting with individuals like N and C, program-specific treatment teams like ours should remain cognizant of the burden to individuals like N of becoming a nonprofessional caregiver to a hand transplant recipient. Understanding caregivers' circumstances can only support our aim of providing excellent care and necessary

expertise in reconstructive transplantation from preoperative consultation through individualized postoperative rehabilitation.

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