

The Chauvet 2014 Meeting Report: Psychiatric and Psychosocial Evaluation and Outcomes of Upper Extremity Grafted Patients

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Abstract: Under the auspices for the International Society on Hand and Composite Tissue Allotransplantation, a section of The Transplantation Society (IHCTAS), a meeting was convened on March 21-22, 2014 in Paris to review the following areas that were deemed significant in the understanding of the psychosocial evaluation and outcomes of upper extremity transplant recipients: required domains of the evaluation, screening instruments, clinical monitoring pretransplant, clinical monitoring posttransplant, patient and team expectations, body image, psychiatric complications, functional goals and quality of life, ethics and media relations. Experts in the fields of psychiatry and psychology, transplantation, social work, ethics, and transplant administration met and reviewed center experiences and literature. The attendees highlighted the importance and the complexity of the psychiatric assessment in this field of transplantation. Moreover, the necessity to develop common instruments and evaluation protocols to predict psychosocial outcomes as well as to understand whether we are transplanting the right patients and how the transplantation is affecting the patients were pointed out. Psychiatric complications in upper extremity transplanted patients have been reported by the majority of teams. Preexisting psychiatric difficulties, the initial trauma of amputation, or adjusting to the transplantation process itself (especially the medical follow-up and rehabilitation process) appeared to be important factors. Monitoring during the whole follow-up was recommended to detect psychiatric issues and to facilitate and ensure long-term adherence. The participants proposed an annual meeting format to build upon the findings of this inaugural meeting to be called the Chauvet Workgroup meeting.

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At the November 2012 American Society of Reconstructive Transplantation meeting, a steering committee was formed to initiate and foster a collaborative international approach to assessing the psychiatric and social issues in upper extremity transplantation. The group named this undertaking the “Chauvet Workgroup” in recognition of the shared effort across centers to collaborate in addressing important questions related to the psychosocial care of these patients. In March 2014, the first international workshop was held in Paris to provide a forum for exchange of information between centers performing upper extremity transplantation. Fourteen teams involved in vascularized composite allotransplantation (VCA) programs participated in the workshop, reporting their experience and evaluation criteria used before and after upper extremity allotransplantation. Furthermore, all the attendees (Appendix 1) discussed on topics that are unique to upper extremity allotransplantation (Table 1) to address the current state of the art in the psychosocial evaluation of upper extremity transplantation recipients. Attendees included specialists in surgery, medicine, psychiatry and psychology, social work, and ethics.

More than 65 patients have undergone upper extremity reconstructive transplantation worldwide: 54% were unilateral and 46% were bilateral upper extremity allotransplantations. The causes determining amputation were motor vehicle and farm accidents, electrical injuries, blast injuries, burns, and sepsis (www.handregistry.com). However, upper extremity transplantation is still a relatively novel treatment,

TABLE 1.**Round table discussion of key issues**

Topics of discussion
Domains of evaluation
Screening instruments
Clinical monitoring before transplantation
Clinical monitoring after transplantation
Patient and team expectations
Description of team roles
Body image
Psychiatric complications
Functional goals and quality of life
Ethics
Media relations

requiring a multidisciplinary approach for the evaluation and management of complex medical, psychiatric, and social issues. Upper extremity transplantation is a life-enhancing procedure, the goal of which is to improve quality of life (QoL). Patients must be highly motivated to undergo rigorous physical therapy and adhere strictly to immunosuppressive medications. Similar to solid organ transplantation, well-selected patients have strong family support, a history of adherence to medical regimens, minimal psychiatric pathology, abstinence from addictive substances if history of abuse,¹ reasonable expectations, and motivation for rehabilitation. A patient's ability to successfully adapt to the complexities of posttransplant life is assessed by a multidisciplinary team of dedicated transplant professionals. A key member of the transplant team is the transplant psychiatrist and/or psychologist, who assesses the patient's risk for psychiatric complications after transplantation. Practitioners may use a variety of psychometric instruments to complement their clinical evaluation. Centers vary widely in terms of the types of instruments used and the weight that the instruments carry in their clinical decision making. No international consensus exists on tools to predict outcome or select candidates.

In this meeting report, we summarize the experience of the participant centers and the discussion that occurred at the meeting with respect to psychosocial assessment and management of upper extremity transplanted patients.

Upper Extremity Transplantation to Date: Updates From the Centers

Pretransplantation: Recipient Selection

Because recipient selection is critical to successful upper extremity transplantation, all of the upper extremity transplant teams performed a psychosocial assessment to evaluate the potential candidates for upper extremity transplantation. The goals of the interview determined: (1) is the patient is an appropriate candidate for transplantation? (2) Will the patient benefit from treatment? (3) What are the patient's expectations for transplantation? (4) How can poor outcomes be minimized?

The providers of the interview were psychiatrists (21.4%) or psychologists (14.3%) or both of them (14.3%), or psychiatrists, psychologists, and social workers (28.6%); in 21.4% of the cases, the provider was not specified. The initial interview for the majority of teams included the following assessments.

(1) Patient-related characteristics

Personality organization (innate personality traits that may help or hinder an individual's ability to respond to stress.)
 Preexisting psychiatric and alcohol/substance dependence history
 Perceived body-image adaptation
 Potential for psychological regression, defined as using primitive coping strategies, such as avoidance, denial, or acting out behavior, such as anger outbursts or oppositional behavior.
 Health behaviors (smoking, exercise, diet)
 History of adherence to medical regimens

(2) Amputation-related characteristics

Functional and occupational impact of amputation
 Coping strategies and adjustment to hand loss
 Prosthetic use
 Pain assessment
 Esthetic concerns

(3) Transplant-related characteristics

Motivation for transplantation
 Expectations
 Emotional and cognitive preparation
 Ability to incorporate a visible deceased donor graft and attitude toward the donor
 Assessment of family/social support
 Financial issues

Although candidates who have suffered blast injuries in the setting of industrial accidents or war could potentially result in cognitive impairment, the attendees did not specifically address cognitive limitations as a barrier to VCA.

Three teams created a screening program based on semistructured clinical interviews. Twelve teams used a battery of tests to evaluate the presence of psychiatric disorders including depression, anxiety, coping abilities, body image, pain measures, health status, and QoL. Rating scales used by teams are reported in Table 2. Of interest, a large majority of teams used the disabilities of the arm, shoulder, and hand (DASH)² even though this is a subjective test used to evaluate upper extremity disability. Four teams used psychometric instruments to evaluate the use/abuse of nicotine, drugs, and alcohol.

Posttransplantation Evaluation Tools and Outcomes

After transplantation, assessments were less structured and less likely to have a particular individual assigned to the task. Seventy percent of the teams evaluated the recipients every 3 months for the first year and every 6 months for 2 to 3 years, then once yearly. Thirty percent of the teams initiated a psychosocial assessment after transplantation only when there were signs of concern.

Three teams specified that the providers were both a psychiatrist and psychologist with the psychiatrist evaluating the patients at least once after transplantation and as needed thereafter, while the psychologist provided regular follow-up.

The large majority of the teams used the following instruments to evaluate the patients during the posttransplant follow-up: Short Form 36,³ DASH,² Hand Transplant Score System,⁴ and self-reported measures of depression and

TABLE 2.
The most common tests used as instruments of evaluation before and after the Tx

Psychometric Instruments	No. Teams Using the Instrument Before Tx	No. Teams Using the Instrument After Tx
PHQ-9 by Spitzer et al, 1999 ⁵	4	0
SF-36/SF-12 Health Survey by Ware et al, 1992, 1996 ^{4,6}	4	1
DSM-IV by American Psychiatric Association, 2000 ⁷	3	2
RSES by Rosenberg, 1965 ⁸	3	2
PAI by Morey, 2007 ⁹	3	0
BAI by Beck et al, 1993 ¹⁰	2	1
MMPI by Hathaway and McKinley, 1943 ¹¹	2	0
PSS-SR by Foa et al, 1997 ¹²	2	0
COPE Inventory by Carver et al, 1989 ¹³	2	1
NEO-PI-R by Costa and McCrae, 1992 ¹⁴	0	2
SSES by Heatherton and Polivy, 1991 ¹⁵	0	2
Self-Report Depression Scale for Research in the General Population (CESD-R) by Radloff, 1977 ¹⁶	0	1
MCS-D Index by Constantine and Ladany, 2000 ¹⁷	0	1

Tx indicates transplantation; PHQ-9, Patient Health Questionnaire; SF, Short Form; DSM-IV, Diagnostic and Statistical Manual-Fourth Edition; RSES, Rosenberg Self-Esteem Scale; PAI, Personality Assessment Inventory; BAI, Beck Anxiety Inventory; MMPI, Minnesota Multiphasic Personality Inventory; PSS-SR, Post-Traumatic Stress Disorder Symptom Scale; COPE, psychometric instruments to assess coping strategies; NEO-PI-R, Neo-Personality Inventory Revised; SSES, State Self-Esteem Scale; CESD-R, Center for Epidemiological Studies Depression Scales Revised; MCS-D, Multicultural Social Desirability; PSS-SR, PTSD Symptom Scale.

anxiety. Moreover, Table 2 lists additional tests used by several teams. A few teams used the same screening tests before and after transplantation.

During the posttransplant period, several psychiatric disorders were reported even though the large majority of the teams reported that their patients were satisfied with the outcome of transplantation. The most common disorders (reported by several teams) were major depression or recurrence of depression, family dysfunction, anxiety disorders, anger issues, and drug or/and alcohol abuse. The teams noted the importance of treating underlying conditions and the need for close monitoring for psychiatric symptoms after transplantation including random urine toxicology screening.

Teams also noted that candidates underestimate the difficulties in the posttransplant period including a decline in the QoL in the first 3 posttransplant months with return to a comparable baseline levels by 1 year after the transplantation. Reports of diminishing QoL may indicate a trend toward worsening of psychiatric symptoms.

Discussion of the Principal Psychosocial Issues in Upper Extremity Transplantation

The principal points emerged during the first Chauvet workshop are reported in Table 3 and are extensively discussed below.

Screening Instruments

Use of extensive batteries of standardized instruments and comprehensive psychosocial interviews has been described in the literature. Uniform guidelines and evaluation protocols describing psychosocial screening instruments to evaluate and provide follow-up for candidates undergoing VCA do not exist^{18,19} or predict outcomes^{20,21} although most centers use an evaluation that incorporates the key domains assessed in common screening instruments²²⁻²⁴ including the Transplant Experience Rating Scale, the Psychosocial Assessment of Candidates for Transplantation, and the Stanford Integrated Psychosocial Assessment for Transplant. Commonly addressed domains in these instruments include history of psychiatric pathology, family support, knowledge about transplantation, substance abuse, and history of compliance with medical care.

Screening tools were considered important for pretransplant and posttransplant data collection and provide additional information to assist decision-making. Ultimate goals were to ensure that the patients were psychosocially likely to come through the transplant experience well and to have fewer long-term costs than benefits. The validity of data on psychosocial outcomes and the development of clinically relevant reference values were limited due to the lack of use of comparable rating scales and standardized assessments. Domains potentially relevant to VCA outcomes (eg, anxiety and depression, personality traits, substance abuse, compliance, QoL, transplant effects/beliefs, coping, and cognitive function) were identified. Posttransplant screening to provide continuous psychosocial follow-up and identify emerging issues is needed. Standardized assessment will facilitate quality improvement, outcome measurement of efficacy, and cost-benefit.²⁵

The participating teams used semistructured clinical interviews to assist in decision making regarding the suitability and eligibility of VCA candidates. Psychiatric history, including conditions that could interfere with the patient's compliance level, as well as coping abilities, personality traits, social support, and environmental factors were important domains.²⁶ Psychosocial screening and follow-up provided an opportunity for supportive psychiatric and/or psychological treatments and have been noted to improve the overall

TABLE 3.
Principal points emerged during the Chauvet workshop

Semistructured evaluation including assessment of self-image, history of trauma, history of adherence, acceptance of deceased donor graft before the transplantation.
Assessment of family acceptance of graft before and after the transplantation
Communication between team members to assist in detection of subtle indications of deteriorating quality of life, psychiatric symptoms after the transplantation.
Team support for the hand therapist due to their potential for transference from the patient.
Detailed discussion of risk and benefits to ensure optimal health literacy.
Attention to developing a media plan that promotes and reasonable understanding of VCA while supporting the privacy needs of patients.
Partnering with ethicists to address issues of justice and optimal informed consent processes.
The need for the development of instrument to measure functional, esthetic and quality of life outcomes for hand transplant patients after the transplantation.

posttransplant outcome.^{18,21,26} In summary, psychiatrists, psychologists, and others should be familiar with the unique issues relevant to VCA transplant patients and be aware of potential instruments.

Pretransplant Psychosocial Assessment

According to participant input the psychosocial assessment was considered important to the successful outcome of transplantation and includes incorporating team feedback about patient interactions. Although a neutral attitude is recommended frequently, the evaluator has to be more active to obtain the necessary information. The quality of contact and of the interaction with the candidate during the interview helps to assess and to develop confidence between the patient and the team.

A primary goal of the interview is to obtain the patient's psychiatric history and the circumstances of the patient's trauma. Assessing how the patient coped with disability including their adaptation to upper limb prosthesis and their assessment of the benefit of transplantation versus prosthesis and identifying posttraumatic stress disorder are particularly important. The past psychiatric history and current symptoms should be explored including anxiety, phobias, depression, suicidality, insomnia, nightmares, addictions, delusions, and personality traits.²⁷

Meeting participants noted that the assessment should include the patient's relationships and social support, and motivation, including expectations of increased function, improvement in body image and perceived importance of hands in communicating (clapping, waving, pointing).

A key component is the evaluation of the patient's capacity to consent to the procedure, what the patient understands of the surgery, the risks, and the rigorous demands of rehabilitation and of posttransplant life.

Whether the candidate has realistic expectations of the transplantation is important. Participants noted that 2 main questions related to patients' expectations: (1) what the patient hopes to gain from the surgery including improved function, decreased pain, recovery of bodily integrity, and restoration of sensation of touch; and (2) whether their expectations are realistic (including surgical risks of immunosuppressives, rejection and graft loss, lifelong immunosuppressive adherence, and rigorous physical rehabilitation). Also paramount is the ability of the patient and transplant team to form a therapeutic relationship with the team, which is critical to adherence with medical recommendations.

The members of the team have to meet and help the family to support the transplant process. It can be also helpful to allow candidates to meet with transplant recipients

Ethical Issues

Helping potential candidates understand the implications of emerging strategies for reconstruction is challenging given the evolving nature of reconstructive surgery and innovations in prosthetic design. Questions related to acceptable risk-benefit ratios need further study. Encouraging the participation of ethicists in the ongoing discussion regarding how patients weigh the risk and benefits of VCA will be important. Improving transplant candidate's health literacy and viewing the informed consent process as an ongoing process that is reinforced over a number of visits may help to optimize candidates' ability to have reasonable expectations about the procedure.

The informed consent process requires careful attention because of the limited worldwide experience in this relatively new field. Patients may be overwhelmed by the amount of information related to the complex medical regimen, lack awareness of the potential for media interest in their experience, and not fully engage in the assessment of the risks of immunosuppressive treatment on posttransplant QoL. Idealization of the outcomes following transplant and unrealistic expectations about the recovery, rehabilitation, and esthetic outcomes can occur. Ongoing discussions with patients to ensure understanding of the implications of proceeding with surgery are needed. Peer mentoring may help the transplant candidate in some cases and warrants research.

Justice issues related to disparities between wealthy candidates and disadvantaged candidates in accessing this form of transplant should be considered because of the relatively few programs offering this transplant option. Wealthy candidates may have the financial resources to travel to distant centers and afford housing near transplant centers during lengthy recovery periods. Securing access to reasonable housing may help offset this barrier to access.

Posttransplant Psychiatric Follow-Up and Complications

During the workshop, it emerged that the resources of individual transplant centers performing VCA vary. Some centers have dedicated psychiatrists or psychologists who evaluate patients and follow up them, whereas others committed social workers. Other centers may have the capability to refer patients to an outside provider if areas of concern are identified.

Psychiatric issues may be subsumed by pressing medical and surgical issues after transplantation. Additionally, patients may confide in nurses and physical therapists. In teams with fewer resources, the hand therapist with whom the patient spends several hours daily may be perceived by the patient as a *de facto* mental health practitioner.

Identifying symptoms that warrant referral to the team psychiatrist or another mental health care provider is important. Key identifiers include even subtle changes in tone of voice, mood, or motivation to participate in physical therapy, missed medical appointments, blood draws, or medications, and may signal distress leading to nonadherence.

Recommendations regarding frequency and length of follow-up after transplantation were not specifically made and varied according to resources and progression of the individual patient's overall status. Participants noted that as intensive hand therapy and surgical follow-up wane in frequency, psychosocial monitoring may help facilitate and ensure adherence long term.

Several centers have reported psychiatric disorders in upper extremity transplant patients at meetings, and there are scattered case reports in the literature. Preexisting psychiatric disorders, the trauma of amputation, or adjusting to the transplantation (especially the medical follow-up and rehabilitation) appear to be important factors. Somatic symptoms may be a sequelae of maladaptive psychological functioning.

Participants noted that mood changes and anxiety frequently occur. Undergoing transplantation, complex medical treatment, and lengthy rehabilitation can lead to mild and temporary depression and anxiety, which may necessitate short-term pharmacologic treatment, especially perioperatively,

during rejection episodes and delayed function, rehabilitation complications, and immunosuppressive side effects. Mood changes and anxiety, although an understandable reaction, may require treatment.

In addition, participants perceived patients with personality disorders require close psychiatric follow-up and may present with an exacerbation or reactivation of maladaptive coping and psychiatric symptoms after transplantation. Prolonged hospitalization and injuries sustained in the initial trauma may contribute to the onset of psychological regression. The patient may become overly dependent on the transplant team or on family members may exhibit helplessness or an immature coping style. Consequently, patients may be less adaptive coping and show mood alterations, addiction, relational difficulties, or behavioral problems including nonadherence with treatment and medical recommendations or conflict with the treatment team. Teams reported that patients may struggle with their identity and relationships with others as a result of the transplantation process. The stress of the procedure can lead to relapsing addictions, potentially putting at risk the ability to manage complex posttransplant medical regimens. Stress may even play a role in the onset of hypertension or diabetes management. On rare occasions after transplantation, patients and family members have been opposed to the transplant, compromising their motivation to manage the medical regimen, leading to graft rejection and necessitating surgical amputation. Psychotic reactions may occur in the setting of high dose opiates, steroid treatment, or by the patient's inability to accept the graft.

Body Image

Body image distortion due to the visible nature of upper extremity transplantation can result in psychological symptomatology and reduced sense of well-being.^{21,25} Concealing behaviors due to negative self-evaluation and potential body image disorder can occur.^{21,28-31} Grafts of a visible organ can lead to a poorly integrated sense of self.

Differences between unilateral versus bilateral amputees were reported during the workshop. Unilateral amputees seemed focused on body image issues. Bilateral amputees seem to experience more severe body image disturbance as well as greater functional limitations. Unilateral amputees must weigh the risk of transplantation against the potentially more limited functional and aesthetic gain.^{18,20} Those disfigured from birth report fewer disturbances than those disfigured from recent injury.^{21,30} Patients with congenital deformation have had more opportunity to incorporate their anomaly into their body image.^{30,32} Amputees who acquire disfigurement later will need to adjust to the circumstances surrounding the onset (eg, trauma, disease, accident), to their loss of function, and appearance and body image changes.²⁸

Teams noted that patients looking at the hand, using the hand for social gestures, and expressing ownership of the hand suggest integration of the hand into the patient's self-image. An inability to psychologically integrate the transplanted hand may result in nonadherence with medications, which in turn will lead to rejection and may necessitate amputation. Projective testing was helpful in identifying positive changes in body image after hand transplantation. Follow-up protocols to assess acceptance of the allograft(s) and adaptation to daily life routines are important.²¹ Teams remarked

that physical and occupation therapy strategies help remodel the sensory motor strip as shown by functional magnetic resonance which could facilitate the patient's reintegration of the hand.

Questionnaires (eg, Rosenberg Self-Esteem Scale, Satisfaction with Appearance Scale, Derriford Appearance Scale), projective tests, and clinical interviews have been used by the different transplant centers to assess body image before and after transplantation.⁸ Body image concerns of the patients' relatives are also important, such as a spouse's concern about being touched with the grafted hands. In some centers, this has resulted in nonadherence leading to graft loss. In summary, the teams suggested that psychosocial interventions to support the transplant candidates in their adaptation to changes in body image using specific psychosocial interventions and training programs would be useful.

Quality of Life

There is a paucity of literature on QoL outcomes in upper extremity transplantation. A recent review identified 27 studies that had examined this issue.¹⁹ The 2 most widely cited instruments are the DASH² and the Hand Transplant Score System.³³ The DASH measures functional outcomes after hand surgery, yields less useful information about the subjective and qualitative experience of the patient, and is not specific to hand transplantation. The Hand Transplant Score System measures psychological and social acceptance, including social behavior, affection, and body image. There is also a section on patient satisfaction, general well-being, and QoL. However, this instrument is weighted to measure functional domain of QoL and is designed for posttransplant assessment only.

Participants noted that functional recovery did not necessarily correlate with QoL, and qualitative measures are needed that capture the subjective experience of the patient. Quality of life is a subjective concept. For some patients, bodily image or a sense of bodily repair may be more important to QoL than functional improvement. For some patients, surgical complications and side effects due to the immunosuppressive treatment may have such a negative impact on their QoL.

The attendees noted that existing measures of QoL in hand transplant do not adequately capture the subjective experience of the patient sufficiently.⁶ The ideal instrument would allow for longitudinal assessment and be culturally and socially sensitive while assessing functional and aesthetic goals. Measurements of QoL including mental health components can serve as useful markers for the patients' overall well-being distinct from specific psychiatric disorders.

Team Roles

Roles will vary depending on the composition of each transplant team, but there was a consensus among the attendees that all programs should have staff identified to support psychosocial needs including, if needed, working with mental health professionals outside the academic center. In addition to ensuring that transplant candidates have sufficient coping mechanisms to undertake complex medical regimens, strong family support, financial stability to ensure housing, transportation, and access to services, the mental health provider must address desensitization/adaptation to the allograft and the development of a new body schema. Recognition of each team member's unique contribution and the creation of a forum

for ongoing communication related to the evolving surgical and medical care of the patient is important as well. Strong leadership by an identified team leader who recognizes the contributions of the mental health providers and supports the emotional burden carried by the hand therapists who spend lengthy amounts of time with the patient can be critical to the success of the transplant.

Media Relations

On the basis of the participants' discussions, media outlets can aid in communicating the availability of innovative strategies for reconstructive surgeries including VCA and ideally allow interested patients to understand the various aspects of transplantation, thus promoting reasonable expectations.

The goals for media involvement include: providing quality updates, ensuring that the media adheres to institutional requirements for confidentiality, and support for potential candidates such as alerting the public to help in other ways, such as blood donation for transplant recipients. A carefully crafted media plan helps protect the patient from inadvertently revealing information that might lead to unsettling speculation by the media. The VCA teams need to understand how the patient and family interact with the media so that media presence will not interfere with medical care.

Indeed, the newsworthy nature of VCA necessitates strategies to ensure patient privacy. Some centers noted marked media interest in their first VCA cases, which necessitated intense efforts to safeguard patient privacy. Patients may not fully appreciate the extent to which their personal life will be impacted by media. Protection of patient privacy necessitates collaboration with security and public affairs staff. Anticipating media interest in donors and donor family is important, and addressing whether the donor family wishes to participate in carefully planned news releases may preempt intrusive experiences with media.³⁴

CONCLUSIONS

We present the international experience to date with the psychosocial assessment of upper extremity transplantation. Although a final consensus on the optimal psychosocial evaluation and management of these patients will likely emerge as the field advances, we identified key domains critical to the psychosocial assessment and which may have an impact on the psychological well-being of the patient after transplantation. The psychosocial assessment and management in vascularized composite tissue transplantation is unique compared to solid organ transplantation, due to the fact that this surgery is a life-enhancing rather than life-saving procedure. Body integrity, quality of life and risk-benefit analysis is more salient in VCA than in solid organ transplantation. The Chauvet meeting highlighted the potential utility of screening instruments specific to upper extremity transplantation to measure these areas, although we note that due to the infancy of this field, no one instrument is considered ideal at this point nor is there 1 uniform strategy for monitoring outcomes post transplant. Combining centers' data and experience would prove helpful in developing common instruments for the evaluation of patients before and after this novel type of transplantation. The attendees support the need for ongoing dialogue and shared research across centers to help refine a standardized psychosocial strategy.

Appendix 1. Listing of All Participants and Their Associated Transplant Programs

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