

ORIGINAL ARTICLE

# The psychological assessment of candidates for reconstructive hand transplantation

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## Summary

Standardized psychological assessment of candidates for reconstructive hand transplantation (RHT) is a new approach in transplantation medicine. Currently, international guidelines and standardized criteria for the evaluation are not established. Patients suffering from the loss of a hand or an upper extremity have to cope with multiple challenges. For a selected group of patients, RHT represents an option for restoring natural function and for regaining daily living independence. The identification of at-risk patients and those requiring ongoing counseling due to poor coping or limited psychological resources are the primary focus of the psychological assessment. We have developed the 'Innsbruck Psychological Screening Program for Reconstructive Transplantation (iRT-PSP)' which utilizes a semi-structured interview and standardized psychological screening procedures and continuous follow-up ratings. Between January 2011 and October 2011, four candidates were evaluated using the iRT-PSP. Psychological impairments including social withdrawal, embarrassment, reduced self-esteem, and a depressive coping style were identified and poor quality of life was reported. The motivation for transplantation was diverse, depending on many factors such as bi- or unilateral impairment, native or accidental loss of hand, and social integration.

## 'Transplant psychology' – General psychological considerations

The human hand represents a powerful physical instrument, with a variety of psychosocial functions and roles. From a psychosocial perspective, the human hand assists in interpersonal communication through touch and gestures. Humans communicate, greet each other, demon-

strate intimacy and love, form and break bonds, protect and attack [1]. Reconstructive hand transplantation (RHT) represents an enormous medical advance involving parts of human anatomy that play such an important role in making us human [2].

Reconstructive hand transplantation has been one of the most striking medical success stories although it differs from other forms of transplantation in numerous

ways [3]. Compared to other forms of transplantation such as solid organ transplantation, RHT was considered less acceptable related to concerns that the recipient's identity would be compromised. Complications of organ rejection and side effects of the immunosuppressant regime, which were considered acceptable for organ transplantations, significantly reduced the probability of proceeding with hand transplantation [4]. Over 60 single and double RHTs have been performed worldwide between 1998 and 2010 and have provided patients with upper extremity amputations the possibility of regaining the ability to experience sensation which cannot be provided by current prostheses and to improve cosmetic outcomes and body image [5]. Hand transplantation also eliminated many other complications and drawbacks related to disability and provided superior functional and aesthetic outcomes [6].

Reconstructive hand transplantation raises questions not only about surgical techniques and immunological procedures but about important ethical and psychological issues. These range from debate about the limits and boundaries of medical intervention [3], to the potential benefits of the technique, the calculation of risk and perceived risk, and the medical and psychological selection, preparation, and management (coping with and adherence to medical regimes) of patients [7]. The functional and sensory outcomes for RHT recipients have been reported [5] but little is known about the psychological outcomes [8,9] and how psychological factors impact quality of life (QoL), compliance, and overall outcomes [5,10].

Despite the developments in transplant medicine in the last two decades, the standardized psychosocial assessment is still a relatively new approach and currently international guidelines and standardized assessment criteria are lacking.

This manuscript is an attempt to discuss issues of a standardized psychosocial assessment of candidates for RHT. We describe the 'Innsbruck Psychological Screening Program for Reconstructive Hand Transplantation (iRT-PSP)', drawing on evidence from previous reported clinical experience and our own experience in the psychosocial assessment of candidates for RHT which includes a generalized assessment of measures of cognitive functioning, affective status, psychosocial adjustment, coping, QoL, and life satisfaction [5,10–23].

## Psychological aspects of transplant surgery

### Adherence and non-adherence

Commitment to a strictly observed immunosuppressive treatment regimen and physical therapy is vital for successful graft viability [24] – e.g. the first bilateral hand transplanted male patient of the Innsbruck Medical University (in year 2000) successfully completed hundreds of

treatment sessions in the last 11 years. Non-adherence has consistently been associated with rejection episodes, graft loss, and death [25–29]. There is a 'dose' effect with additional numbers of risk factors including pre-morbid psychiatric status, poor social support, substance abuse and psychological status (e.g. high anxiety) which are also important dimensions for pre-surgical assessment. Non-adherence post operatively is predicted by pre-transplant non-adherence [26]. Alternatively, self-efficacy, or the belief that one is clearly competent to perform a behavior, is a good predictor of maintenance behavior (e.g. handling with prosthesis) [30]. In terms of psychological models which would be useful in further studying the relationship between pre and post transplant compliance, the theory of planned behavior would appear to provide a useful framework. Goetzman and colleagues [31] have verified the positive impact of social support on coping and health behavior for transplant patients. These predictive dimensions should be considered especially in the pre-transplant psychosocial assessment to evaluate patients' pre- and post-surgical compliance level.

## Motivational aspects for reconstructive hand transplantation

The motivation for RHT is diverse and depends on many factors including bi- or unilateral impairment, native or accidental loss of hand, social integration, and the physical or psychological status of the patients. Generally, difficulties with coping and psychological burden are motivation factors primarily reported by patients having lost one hand as opposed to bilateral amputees who are motivated by the need for increased function. An integral role of psychosocial assessment is to assess the decision making process to ensure that patients have sufficient information regarding the benefits and risks of surgery and to assess their motivation [7].

According to Brunier *et al.* [32] and Petrie [33], peer education in the interpersonal exchange between transplantation candidates and patients that had already undergone uni-/bilateral RHT is another important factor to help the candidates in their decision-making process. Uniquely, the iRT-PSP establishes a peer mentoring strategy allowing candidates and patients with uni-/bilateral tissue allografts to meet.

## Recent acute injured patients versus chronic stable patients

Several issues are unique to the assessment of RHT patients. The management of recent acute injury is very different from the management of chronic stable patients who may be many years post injury and come with high level of physical and psychological adaptation. Hence, it

is important to set out exactly what is being proposed before there can be any meaningful development of a protocol for patient assessment [7]. The aetiology of the visible difference in body image distress and psychosocial adjustment is significant [34] with people disfigured from birth reporting less disturbance than those disfigured from 'recent' accidental injury. People with congenital deformation will have had more opportunity to incorporate their anomaly into their body image, to habituate to the response of others, and to acquire effective coping strategies [35]. People who acquire disfigurement later in life have to deal with their reactions to the circumstances surrounding the onset (e.g. trauma, disease, accident), to the loss of their functional performance and previous looks, and to changes to their body image [36].

### Decision-making process

The major barrier to this kind of surgery is the serious problem of immunosuppression which is likely to result in reduced immune response, increased tumor risk, and eventually in reduced life expectancy in addition to compromises in QoL. In assessing patients' understanding of the procedure, it will be important to elicit the individual's understanding of the long term effects of immunosuppression, and to provide information about risk in a way patients can apply to themselves [7]. Decision-making can be especially stressful for patients when the aesthetic outcome is uncertain and when multiple treatment options are available [37].

The evaluation of the patient's motivation represents an essential element in the psychological assessment of potential candidates for uni-/bilateral RHT. The mismatch between surgical team's expectation about the outcome and patients' can lead to difficulties in determining when treatment is finished [37,38]. Similarly, although the perception of particular body feature may improve following surgery, this does not have a corresponding impact on overall perception of body image [39]. Hence, the preparation for surgery in any reconstructive setting involves the careful assessment of patient's expectation and challenging unrealistic expectations. Surgery, even when technically successful, is not a treatment to resolve longstanding body image and other dilemmas [7].

### Body image and self-concept

The disturbed body image due to the loss of a hand is a major factor resulting in reduced psychological and social well being. Patients live with physical deficits, cope with increased psychological distress, and have to compensate for potential social pressure. Many patients experience self-consciousness about conspicuous physical differences

resulting in shame, and which may trigger a range of concealing behaviors in response to negative self-evaluation [1,30,40–43].

The evaluation of body image in candidates for RHT has to assess different types and body sites, the variability in severity and visibility, and the numerous personal, social, and situational characteristics that contribute to body image and adjustment [40,41,44]. A person's subjective perception of visible disfigurement represents the best predictor of psychological and body image disturbances [45]. Candidates for reconstructive transplantation, who are visibly different, report problems related to negative self-perceptions [46–48] and difficulties with social interaction [37]. These problems frequently involve spirals of negative emotions (e.g. social anxiety), maladaptive thought processes (e.g. fear of negative social evaluation), unfavorable self-perceptions (e.g. lowered self-esteem and favorable body image), and negative behavior patterns (e.g. excessive social avoidance) [37]. Because of the complexity of involved processes, the psychological difficulties of people experiencing threats of their body image are similar to those suffered by people with social phobia [35].

The assessment of the self-concept of hand transplant candidates represents an essential aim of the standardized psychosocial evaluation process which addresses the psychological impact of disfigurement [37]. Furthermore, a patient-centered assessment of the impact of surgical intervention on appearance and function is needed [49,50]. To avoid an isolated psychological measurement of just one or two elements, a balance between comprehensive assessment and an excessive battery of questionnaires is needed to address the emotional, behavioral, cognitive, and physical changes resulting from the surgical intervention [37].

### Psychological considerations in the debate regarding uni- versus bilateral reconstructive hand transplantation

In the debate of potential psychological assets and drawbacks of uni-/bilateral RHT the already mentioned patient's body- and self-concept should be particularly taken into account. Based on our clinical experience, the surgical restoration of their damaged (distorted) body- and self-concept represents one of their central motivational aspects for surgery especially for freshly injured candidates for hand transplantation.

Therefore, in this discussion we make a distinction between the uni-/bilateral RHT for freshly injured patients and candidates that have been handicapped for many years and have learned to integrate the bodily impairment in their individual body- and self-concept. These candidates have learned to live and cope with their

bodily imperfection. In contrast, patients that suffer from recent traumatic injury are used to have a fully functioning body and initially have to adapt to their bodily impairment. Thus, the recovery of full physical functionality and integrity represents an essential motivation for reconstructive restoration of their hand/hands for many recently injured patients. Ultimately, motivation, coping skills, compliance, body- and self-concept, and QoL, can be evaluated during the initial psychological assessment and with continuous follow-up ratings.

### **Innsbruck psychological screening program for reconstructive transplantation**

Based on our clinical experience with hand transplant patients we have developed the iRT-PSP as a standardized assessment protocol. Several development periods have been necessary to develop the actual protocol version that still is under development. Because of multiple steps of protocol design, those discussed here represent the psychometric results of evaluated candidates using a previous protocol version (see Table 3: psychometric results of evaluated candidates for RHT).

In order to assess potential candidates for uni-/bilateral RHT, a semi-structured interview (see Table 1: psychosocial characteristics of the structured interview for the assessment of candidates for hand transplantation) addressing motivational aspects, coping skills, general compliance, body- and self-concept, QoL for reconstructive surgery is essential [51]. The psychological assessment should ensure that standardized psychological screening procedures and continuous follow-up ratings of the patients for uni-/bilateral RHT [51] by the application of a battery of psychometric tests are undertaken (see Table 2: psychometric instruments of the iRT-PSP battery).

Furthermore, the iRT-PSP provides a standardized protocol not only for pre-transplant assessment of potential eligible transplant candidates but also for pre-, peri- and post-operative follow-up ratings. In addition, patients requiring treatment can be identified quickly and where appropriate supportive psychological and/or psychiatric treatment can be indicated [51].

Psychosocial appropriateness can be determined by a clinical interviewer adequately familiarized with the population and who identifies patients who will comply with the rigorous postoperative transplant course. The semi-structured psychological interview should ensure the evaluation of key psychosocial domains in transplantation and is based on the psychosocial concepts identified in the 'Transplant Evaluation Rating Scale (TERS)' [52].

Gathering interview data in a structured and standardized manner increases the likelihood that relevant information will be obtained [53] and optimizes the

systematic collection of data that could be used to investigate psychosocial factors that are used in clinical decision making in transplantation [52,54]. The iRT-PSP interview protocol highlights areas that are specific to RHT and gives clinicians an immediate understanding of what type of information is necessary to conduct a comprehensive psychosocial assessment.

For further validation of the results from the semi-structured psychosocial interview, the application of the following battery of psychosocial scales is recommended (see Table 2: psychometric instruments of the iRT-PSP battery).

An interdisciplinary discussion of previously recorded patients' data ensures a thorough decision-making process regarding the potential uni-/bilateral RHT which can be combined with the standardized assessment protocols providing identification of at-risk patients and the need for supportive psychological treatments. Reevaluation over time is needed to provide continuous monitoring.

Low-risk candidates (transplant candidacy with no contingencies) typically have greater psychological stability and adjustment, medical compliance, are more interested in the treatment options and the course of RHT, and a healthier lifestyle than high-risk candidates (transplant candidacy refused or contingent on behavioral changes). The iRT-PSP assists in the development of behavioral recommendations that help patients become more appropriate transplant candidates and is used for interdisciplinary decision-making process of the interdisciplinary workgroup 'Reconstructive Transplantation Innsbruck (RTi)'.

Interventions for managing life stress and detecting and treating psychological distress should be offered pre-transplantation to prepare candidates for the challenges they may face after transplantation including lifelong adherence to medications [79].

### **Subjects and results of preoperative psychological assessment**

Between January and October 2011, four candidates for uni-/bilateral RHT underwent pre-transplant surgical and psychological assessment (iRT-PSP) at the Innsbruck Medical University. After institutional approval and adequate informed consent, all four candidates entered the surgical, immunological, and psychological assessment.

Although the four screened candidates had a different history of hand loss and showed diverse psychological reactions, all had on common aim: reconstructive hand transplantation.

Candidate A was a 49-year-old female patient who suffered a high-voltage electrical injury in early adolescence. She lost her right forearm and also her left hand was functionally impaired because of the high-voltage accident. By using an aesthetical prosthesis, the patient described a

**Table 1.** Psychosocial topics of the structured interview for the assessment of candidates for uni-/bilateral reconstructive hand transplantation.

Psychosocial interview guide for the assessment of candidates for uni-/bilateral reconstructive hand transplantation		Severity index	
#	Psychosocial characteristics		
I	Prior psychiatric history (weight = 4.0)	DSM-IV axis 1 and axis 2 diagnoses, and associated prior psychiatric, psychological, and/or psychotherapeutic treatment	0 1 2 3
II	Daily activities (weight = 4.0)	Daily activities, individual degree of independent scheduling of day-time activities	0 1 2 3
III	Personal, functional and aesthetical aspects (weight = 4.0)	Realistic appreciation of functional and aesthetical aspects, personal attributes	0 1 2 3
IV	Personal decision (weight = 4.0)	Quality of the individual decision-making process, evaluated stability and scope of personal choice	0 1 2 3
V	Education and information (weight = 4.0)	Individual information level, quality of independent collection of information and evaluation of existing information exchange, open questions and uncertainties, realistic appreciation of the risk-benefit ratio - especially with regard to the significantly increased cancer risk because of immunosuppression	0 1 2 3
VI	Traumatic reactions (weight = 3.0)	Potentially traumatic reactions due to the loss of one hand or both hands, and associated coping strategies (according to DSM-IV criteria)	0 1 2 3
VII	Hand fantasies (weight = 3.0)	Fantasies and visions concerning the donor organ, associations regarding the donor and his lifestyle	0 1 2 3
VIII	Anxiety (weight = 3.0)	Quality of anxious beliefs toward the potential hand transplantation, previous personal surgical experiences	0 1 2 3
IX	Substance use/abuse (weight = 3.0)	General alcohol, tobacco, and/or drug use/abuse (according to DSM-IV criteria)	0 1 2 3
X	Adherence (weight = 3.0)	Individual adherence level especially taking the potential postoperative immunosuppressive treatment and associated therapeutic issues into account	0 1 2 3
XI	Health behaviors (weight = 2.5)	General lifestyle, exercise, and eating patterns	0 1 2 3
XII	Quality of family/social support (weight = 2.5)	Quality of interpersonal relationships and social network, general reactions of the social environment regarding the potential hand transplantation	0 1 2 3
XIII	Prior history of coping and stress management	Repertoire of coping behaviors and stress management, specific behavior patterns regarding the physical impairment	0 1 2 3
XIV	Treatment alternatives (weight = 2.0)	Alternative treatment approaches, e.g. prosthetic restoration of physical impairment	0 1 2 3
XV	Quality of affect (weight = 1.5)	Affect quality, appropriate experience of anxiety, fear, and sadness	0 1 2 3
XVI	Mental status (weight = 1.0)	General cognitive level	0 1 2 3

Notes: Severity determination of psychosocial characteristics: 0, not applicable; 1, without pathological finding; 2, minimal to average symptom level; 3, maximal symptom level. Weighted cumulative value derived by multiplying the candidate's rated level on each subscale (1, 2, or 3) by the assigned weight of the subscale and then summing across the 16 subscales.

**Table 2.** Psychometric instruments of the 'Innsbruck Psychological Screening Program for Reconstructive Transplantation (iRT-PSP)' and appendent constructs.

Alcohol Use Disorders Identification Test (Audit-C) by Kriston <i>et al.</i> [55]; German version by Dybek <i>et al.</i> [56]*	Assessment of alcohol use history
Fagerström Test for Nicotine Dependence (FTND) by Heatherton <i>et al.</i> [57]; German version 'Fagerström-Test für Nikotinabhängigkeit (FTNA)' by Bleich <i>et al.</i> [58]*	Standardized assessment of nicotine use
Fragebogen zum Körperbild (FKB-20) by Clement & Löwe [59]; English version 'Body Image Questionnaire (BIQ-20)' by Kumnig <i>et al.</i> (in progress)* [additional items to evaluate potential organ fantasies]	Questionnaire to measure body image and organ fantasies
Generalized Anxiety Scale (GAD-7) by Spitzer <i>et al.</i> [60]; German version by Löwe <i>et al.</i> [61]*	Evaluation of anxiety
Medication Experience Scale for Immunosuppressants; German version 'Medikamentenwirkungs-Erfahrungs-Skala für Immunsuppressiva (MESI)' by Goetzmann <i>et al.</i> [62]†	German scale to evaluate the compliance focusing on immunosuppression
SF-36/SF-12 Health Survey by Ware <i>et al.</i> [63]; German version by Bullinger & Kirchberger [64]*	Survey to measure QoL
Patient Health Questionnaire (PHQ) by Spitzer <i>et al.</i> [65]; German version 'Gesundheitsfragebogen für Patienten (PHQ-D)' by Löwe <i>et al.</i> [66]*	Evaluation of depression
Response Evaluation Measure (REM-71) by Steiner <i>et al.</i> [67]; German version 'Abwehrfragebogen (AF-2003)' by Mitmansgruber <i>et al.</i> [68]*	Survey to evaluate individual's defense mechanism
Scales of Psychological Well-Being (PWB) by Ryff & Keyes [69]; German version by Staudinger <i>et al.</i> [70]*	Psychological well-being survey
Sense of Coherence Scale, Short Form (SOC-13) by Antonovsky [71]; German version by Schumacher <i>et al.</i> [72]*	Sense of coherence
Transplant Effect Scale (TxEQ) by Ziegelmann <i>et al.</i> [24]; German version by Klaghofer <i>et al.</i> [73]†	Scale to measure potential transplant effects afterwards (e.g., adherence, responsibility, etc.)

Notes: \*Psychometric instrument adapted for baseline and follow-up psychological assessment procedures.

†Additional psychometric instrument used only for follow-up ratings.

moderate functional impairment in her daily routines. Especially her reduced QoL but also aesthetical aspects and her bodily dissatisfaction motivated her for unilateral RHT.

In contrast, candidate B was a 22-year old male patient who suffered from the congenital loss of left hand. Related to his congenital hand loss, the patient reported a high level of functional adaptation. Because of his high degree of adaptation, severe mental disorders were not detected. Despite his high functional level, his lack of a left hand and his desire to optimize his functionality primarily motivated him for pre-transplant screening for unilateral RHT.

In case C, a recent woodwork accident was responsible for a 41-year-old male patient losing his right hand and forearm (incl. elbow joint) 1 year before. To increase patient's functionality, he got a myoelectrical prosthesis following 10 weeks of rehabilitation, but he did not use the prosthesis for his daily routines. Notably, the patient described no functional benefit of using his myoelectrical prosthesis. Furthermore, his phantom pain and the desire to re-establish his almost full functionality effected his decision making process. Hence, the pre-transplant psychological assessment evaluated traumatic reactions and problems to coping with changed life.

Candidate D also suffered from recent bilateral hand loss because attempted suicide (in year 2009). Of all evaluated candidates, candidate D reported the highest level of functional impairment. Furthermore, he suffered also

from severe facial burns that made a comprehensive rehabilitation necessary. Primarily his massive functional impairment was responsible for his motivation for RHT but also he was influenced by a desire to resolve body image concerns. Subsequently, a transfer of attention from his hand loss to his facial distortion could be anticipated after potential RHT. This issue should be an area of particular attention when considering supportive psychological treatment of candidate D.

The iRT-PSP provided a standardized preoperative psychosocial assessment. Hence, the interdisciplinary decision making process, regarding the eligibility of all four candidates for potential uni-/bilateral RHT, was based on these main findings of the preoperative assessment procedure (psychometric testing and semi-structured interview).

Subsequently psychometric screening results describe essential psychosocial similarities and also major differences of screened candidates that allow a better understanding about psychosocial preconditions for uni-/bilateral RHT (Table 3).

### Response Evaluation Measure (REM-71)

In the psychosocial assessment of candidates for RHT, the concept of defense is especially useful. The REM-71 differentiates between the 'immature' and 'mature' cluster. The immature cluster contains defenses that distort reality

**Table 3.** Exemplary psychometric iRT-PSP screening results of the evaluated candidates for uni-/bilateral reconstructive hand transplantation.

Psychometric iRT-PSP results	Case A ♀, 49 years, unilateral RHT, office manager	Case B ♂, 22 years, unilateral RHT, student	Case C ♂, 41 years, unilateral RHT, techn. administrator	Case D ♂, 54 years, bilateral RHT, surveying technician
Brief symptom inventory (BSI)* by Derogatis <i>et al.</i> [74]; German version by Franke [75] <sup>B</sup>				
	T-values (cutoff score >65)			
Hostility	38 <sup>A</sup>	55 <sup>A</sup>	55 <sup>A</sup>	55 <sup>A</sup>
Anxiety	52 <sup>A</sup>	48 <sup>A</sup>	52 <sup>A</sup>	57 <sup>A</sup>
Depression	50 <sup>A</sup>	41 <sup>A</sup>	55 <sup>A</sup>	55 <sup>A</sup>
Paranoid ideation	41 <sup>A</sup>	41 <sup>A</sup>	54 <sup>A</sup>	41 <sup>A</sup>
Phobic anxiety	45 <sup>A</sup>	45 <sup>A</sup>	45 <sup>A</sup>	55 <sup>A</sup>
Psychoticism	44 <sup>A</sup>	44 <sup>A</sup>	54 <sup>A</sup>	44 <sup>A</sup>
Somatization	54 <sup>A</sup>	40 <sup>A</sup>	54 <sup>A</sup>	40 <sup>A</sup>
Obsessive-compulsive	35 <sup>BA</sup>	43 <sup>A</sup>	55 <sup>A</sup>	35 <sup>BA</sup>
Interpersonal sensitivity	48 <sup>A</sup>	40 <sup>A</sup>	48 <sup>A</sup>	40 <sup>A</sup>
PSDI (positive symptom distress index)	40 <sup>A</sup>	40 <sup>A</sup>	48 <sup>A</sup>	41 <sup>A</sup>
PST (positive symptom total)	40 <sup>A</sup>	41 <sup>A</sup>	55 <sup>A</sup>	46 <sup>A</sup>
GSI (global severity index)	40 <sup>A</sup>	39 <sup>BA</sup>	55 <sup>A</sup>	45 <sup>A</sup>
Essener coping questionnaire* ('Essener Fragebogen zur Krankheitsverarbeitung, EFK') by Franke <i>et al.</i> [76] <sup>B</sup> (German questionnaire to measure disease associated coping skills; adapted for uni-/bilateral hand transplantation)				
	T-values			
Acting and problem-oriented coping	57 <sup>A</sup>	65 <sup>AA</sup>	53 <sup>A</sup>	65 <sup>AA</sup>
Distance and self development	42 <sup>A</sup>	51 <sup>A</sup>	44 <sup>A</sup>	39 <sup>BA</sup>
Information seeking and exchange of experiences	65 <sup>AA</sup>	65 <sup>AA</sup>	39 <sup>BA</sup>	51 <sup>A</sup>
Extenuation, wishful thinking, and threat defense	46 <sup>A</sup>	47 <sup>A</sup>	67 <sup>AA</sup>	39 <sup>BA</sup>
Depressive reactions	55 <sup>A</sup>	54 <sup>A</sup>	65 <sup>AA</sup>	54 <sup>A</sup>
Willingness to accept help	49 <sup>A</sup>	50 <sup>A</sup>	39 <sup>BA</sup>	61 <sup>AA</sup>
Active searching for social integration	47 <sup>A</sup>	48 <sup>A</sup>	51 <sup>A</sup>	61 <sup>AA</sup>
Trust in medical care	62 <sup>AA</sup>	61 <sup>AA</sup>	66 <sup>AA</sup>	61 <sup>AA</sup>
Development of internal support	46 <sup>A</sup>	49 <sup>A</sup>	50 <sup>A</sup>	61 <sup>AA</sup>
Life Orientation Test-Revised (LOT-R)* by Carver, Scheier & Bridges [77]; German version by Glaesmer, Hoyer, Klotsche & Herzberg [78] <sup>B</sup>				
	T-values			
Optimism	66 <sup>AA</sup>	51 <sup>A</sup>	39 <sup>A</sup>	56 <sup>A</sup>
Pessimism	51 <sup>A</sup>	49 <sup>A</sup>	46 <sup>A</sup>	58 <sup>A</sup>
Global index	63 <sup>AA</sup>	50 <sup>A</sup>	39 <sup>A</sup>	59 <sup>A</sup>
Body Image Questionnaire ('Fragebogen zum Körperbild, FKB-20') by Clement & Löwe [59]; English version by Kumnig <i>et al.</i> (in progress) <sup>B</sup>				
	T-values			
Negative body evaluation	73 <sup>AA</sup>	37 <sup>BA</sup>	53 <sup>A</sup>	47 <sup>A</sup>
Vital body dynamics	40 <sup>BA</sup>	63 <sup>AA</sup>	58 <sup>A</sup>	59 <sup>A</sup>
Patient Health Questionnaire (PHQ) by Spitzer <i>et al.</i> [65]; German version 'Gesundheitsfragebogen für Patienten (PHQ-D)' by Löwe <i>et al.</i> [66] <sup>B</sup>				
	Depression & anxiety index			
PHQ-9 depression scale	None-minimal	None-minimal	None-minimal	None-minimal
GAD-7 anxiety scale	None-minimal	None-minimal	None-minimal	None-minimal

**Table 3.** continued

	Case A ♀, 49 years, unilateral RHT, office manager	Case B ♂, 22 years, unilateral RHT, student	Case C ♂, 41 years, unilateral RHT, techn. administrator	Case D ♂, 54 years, bilateral RHT, surveying technician
Psychometric iRT-PSP results				
Response Evaluation Measure (REM-71) by Steiner et al. [67]; German version 'Abwehrfragebogen (AF-2003)' by Mitmansgruber et al. [68] <sup>B</sup>				
	T-values			
Factor 1: 'Immature' cluster	54 <sup>A</sup>	51 <sup>A</sup>	53 <sup>A</sup>	52 <sup>A</sup>
Acting out	54 <sup>A</sup>	62 <sup>AA</sup>	46 <sup>A</sup>	27 <sup>BA</sup>
Conversion	27 <sup>BA</sup>	27 <sup>BA</sup>	27 <sup>BA</sup>	27 <sup>BA</sup>
Displacement	58 <sup>A</sup>	27 <sup>BA</sup>	54 <sup>A</sup>	27 <sup>BA</sup>
Dissociation	48 <sup>A</sup>	48 <sup>A</sup>	48 <sup>A</sup>	27 <sup>BA</sup>
Fantasy	57 <sup>A</sup>	56 <sup>A</sup>	27 <sup>BA</sup>	44 <sup>A</sup>
Omnipotence	57 <sup>A</sup>	53 <sup>A</sup>	53 <sup>A</sup>	61 <sup>AA</sup>
Passive-aggression	58 <sup>A</sup>	53 <sup>A</sup>	71 <sup>AA</sup>	62 <sup>AA</sup>
Projection	56 <sup>A</sup>	27 <sup>BA</sup>	27 <sup>BA</sup>	27 <sup>BA</sup>
Repression	50 <sup>A</sup>	57 <sup>A</sup>	57 <sup>A</sup>	69 <sup>AA</sup>
Somatization	53 <sup>A</sup>	46 <sup>A</sup>	56 <sup>A</sup>	50 <sup>A</sup>
Splitting	55 <sup>A</sup>	61 <sup>AA</sup>	45 <sup>BA</sup>	27 <sup>BA</sup>
Sublimation	62 <sup>AA</sup>	58 <sup>A</sup>	53 <sup>A</sup>	61 <sup>AA</sup>
Undoing	51 <sup>A</sup>	51 <sup>A</sup>	48 <sup>A</sup>	68 <sup>AA</sup>
Withdrawal	53 <sup>A</sup>	54 <sup>A</sup>	66 <sup>AA</sup>	58 <sup>A</sup>
Factor 2: 'Mature' cluster	71 <sup>AA</sup>	55 <sup>A</sup>	47 <sup>A</sup>	66 <sup>AA</sup>
Altruism	56 <sup>A</sup>	37 <sup>BA</sup>	40 <sup>BA</sup>	52 <sup>A</sup>
Denial (isolation of affect)	61 <sup>AA</sup>	53 <sup>A</sup>	53 <sup>A</sup>	68 <sup>AA</sup>
Humor	68 <sup>AA</sup>	55 <sup>A</sup>	43 <sup>A</sup>	47 <sup>A</sup>
Idealization	53 <sup>A</sup>	53 <sup>A</sup>	74 <sup>AA</sup>	60 <sup>A</sup>
Intellectualization	61 <sup>AA</sup>	61 <sup>AA</sup>	54 <sup>A</sup>	62 <sup>AA</sup>
Reaction formation	64 <sup>AA</sup>	49 <sup>A</sup>	71 <sup>AA</sup>	67 <sup>AA</sup>
Suppression	66 <sup>AA</sup>	63 <sup>AA</sup>	40 <sup>BA</sup>	68 <sup>AA</sup>
SF-36 Health Survey by Ware et al. [63]; German version by Bullinger & Kirchberger [64] <sup>B</sup>				
	T-values			
Physical functioning	50 <sup>A</sup>	50 <sup>A</sup>	43 <sup>BA</sup>	51 <sup>A</sup>
Role-physical	50 <sup>A</sup>	50 <sup>A</sup>	37 <sup>BA</sup>	27 <sup>BA</sup>
Bodily pain	49 <sup>A</sup>	50 <sup>A</sup>	40 <sup>BA</sup>	50 <sup>A</sup>
General health	62 <sup>AA</sup>	61 <sup>AA</sup>	50 <sup>A</sup>	62 <sup>AA</sup>
Vitality	60 <sup>AA</sup>	51 <sup>A</sup>	41 <sup>BA</sup>	51 <sup>A</sup>
Social functioning	49 <sup>A</sup>	51 <sup>A</sup>	50 <sup>A</sup>	49 <sup>A</sup>
Role-emotional	49 <sup>A</sup>	50 <sup>A</sup>	50 <sup>A</sup>	48 <sup>A</sup>
Mental health	38 <sup>BA</sup>	51 <sup>A</sup>	48 <sup>A</sup>	48 <sup>A</sup>
Transplant Effect Scale (TxEQ) by Ziegelmann et al. [24]; German version by Klaghofer et al. [73] <sup>B</sup>				
	T-values			
Worry about transplant	43 <sup>A</sup>	64 <sup>AA</sup>	51 <sup>A</sup>	51 <sup>A</sup>
Guilt regarding donor	63 <sup>AA</sup>	51 <sup>A</sup>	54 <sup>A</sup>	51 <sup>A</sup>
Disclosure	67 <sup>AA</sup>	62 <sup>AA</sup>	67 <sup>AA</sup>	50 <sup>A</sup>
Adherence	59 <sup>A</sup>	56 <sup>A</sup>	32 <sup>BA</sup>	56 <sup>A</sup>
Responsibility	38 <sup>BA</sup>	52 <sup>A</sup>	50 <sup>A</sup>	52 <sup>A</sup>

Notes: \*The prefinal version of the iRT-PSP used the BSI, EFK, and LOT-R for comprehensive preoperative psychological assessment of candidates for uni-/bilateral hand transplantation. The final version of the iRT-PSP doesn't include the BSI, EFK, and LOT-R, instead the Audit-C, FTND, GAD-7, PWB, and SOC-13 have been added. T-values have been calculated to compare the iRT-PSP results of evaluated candidates with norm samples. Severity index (compared to norm samples): BA, below average; A, average; AA, above average. B, Psychometric instrument adapted for baseline psychological assessment procedures.



in accordance to expected outcomes, leading to less adaptive functioning. Mature defenses attenuate unwelcome reality, allowing more adaptive functioning [67].

All four candidates showed below average results on the conversion scale (sample item: '*Sometimes I have lost all the feeling in one part of my body and nobody could explain why*'). Further REM-71 results of all four patients are diverse and no common defense concept for RHT patients could be evaluated.

### Brief Symptom Inventory (BSI)

The BSI instrument assesses patients' level of psychological problems and provides patient-reported outcomes measurement for treatment programs. The BSI results of all four candidates showed no clinical relevant findings.

### Essener Coping Questionnaire (EFK)

The fact that almost all CTA-teams reported problems of non-compliance of recipients, their ability to cope with disease and/or physical handicap is especially important in assessing candidate's eligibility for RHT. The EFK was used to investigate candidates' coping archetypes.

The trust in medical care was above-average in all four RHT candidates. Furthermore, two patients highlighted information seeking and exchange of experience as very important for their decision for RHT. As a positive coping resource, candidates B and D showed high levels of self efficacy and problem-oriented coping. Candidate D could also utilize internal support, but his self development was evaluated as insufficient. Because of his bilateral hand loss and associated social adverse effects, candidate D reported also high levels of active searching for social integration. Whereas candidate C showed above-average depressive reactions (equivalent BSI results are missing) and extenuation, wishful thinking and threat defense. Furthermore, candidate C showed reduced willingness to accept help, correlating with his strong desire for autonomy and his motivation for RHT.

### Life Orientation Test-Revised (LOT-R)

The LOT-R was developed to assess individual differences in generalized optimism versus pessimism. The generalized optimism and pessimism scores of all four candidates showed average levels. Only candidate A was very optimistic regarding her potential RHT.

### Body Image Questionnaire (FKB-20)

Candidates for RHT, who are visibly different, report many problems related to negative self-perceptions [47]

and are more at risk for body image disturbances, but not all are equally affected [40].

Our candidates showed diverse results regarding their body image evaluation. Candidate A described a massive negative body evaluation and reduced values on the FKB-20 scale 'vital body dynamics' that correlated with her socially anxious behavior. Whereas, candidate B could adequately integrate his native hand loss with his body/self concept. Furthermore, candidates C and D showed no body image disturbance.

### Patient Health Questionnaire (PHQ)

The PHQ offers a concise, self-administered screening and diagnostic tool for mental health disorders. Using generalized depression and anxiety instruments, all four candidates showed none to minimal depressive and anxious symptoms.

### SF-36 Health Survey

The SF-36 scores of candidates A, B and D were predominantly at average levels. Candidate C reported reduced QoL on several SF-36 scales, especially regarding his physical functioning and physical role, his vitality, and experience of bodily pain. Candidate C's low level of QoL demonstrated his problems integrating his hand loss in his body concept and daily routines. Because of his bilateral hand loss, candidate D reported also a reduced physical role function that represented his reduced physical functionality.

### Transplant Effect Scale (TxEQ)

All four candidates disclosed their decision for uni-/bilateral RHT. Candidate A felt guilt regarding the potential donor, whereas candidate B worried about the transplant. Particularly remarkable was the low adherence level of candidate C that could have a potential influence on the postoperative treatment and rehabilitation (e.g. compliance with immunosuppression). Therefore, the preoperative psychological assessment should ensure an individual assessment of candidates' emotional responses to potential RHT.

## Discussion

For patients contemplating reconstructive hand transplantation, realistic expectations of outcome and knowledge of the potential risk factors are the best predictors for satisfaction after reconstructive treatment. Understanding what the patient already knows (e.g. by

assessing the patient's education and information level), reinforcing beliefs that are accurate and modifying those that are inaccurate as a first step, before introducing ideas that may be new maximizes understanding and recall [7]. Determining resources that protect against the development of psychiatric disturbances and facilitate a healthy adjustment to life stresses can be investigated in pretransplant candidates interested in RHT [80].

It is critically important that a standardized assessment protocol is established to collect and investigate objective data [54]. Little research exists on psychiatric outcomes for hand transplant patients. Multicenter studies, to determine factors that support/influence the outcome, are needed [7].

Differences between uni-/bilateral RHT candidates constitute one area of research as are issues related to body image and expectations of transplant impact on body perception. Future research would then help in the development of enhanced assessment and screening programs to address these unique concerns.

The current psychosocial assessment and preparation of candidates for RHT are drawn from research findings in organ transplantation [7]. Because of the likely presence of psychiatric comorbidity in transplant patients, the literature stresses the importance of psychosocial assessment and intervention [81–83].

A detailed understanding of how an injury has impacted on patients' life, whether they have adapted well to their disability, whether they understand and have had access to psychosocial intervention and what they see as the remaining specific goals for treatment [84] is the primary task of the evaluation. Additionally, their understanding of the procedure, benefits and risks of hand transplantation, their functional and aesthetical expectations of post-operative change, and their likely engagement with post-operative management are evaluated. Research indicates the need for supportive psychological treatment not only during the pre-transplant phase, but also during the post-transplant phase and associated follow-ups [85]. These postoperative interventions should be a required part of the comprehensive interdisciplinary collaborations within the team. The psychosocial and surgical assessment of candidates for RHT should be made in the context of an interdisciplinary transplant team that reassesses the patient at multiple timepoints to ensure that no new adverse symptoms or increasing stressors have developed.

Further investigations should assure that reconstructive hand transplantation programs develop thoughtful and well planned clinical research protocols that address unique aspects of hand transplantation including QoL

outcomes, the impact of body image concerns and expectations for outcome following transplant.

### Authorship

MK: designed research, performed research, collected data, analyzed data, wrote the paper. SGJ: designed research, wrote the paper. GR: designed research, performed research, wrote the paper. AW, TH and TOE: collected data, wrote the paper. GB, MG, MN, MR, BZ, MB, RM, GP and JP: contributed important reagents. BZ: wrote the paper, contributed important reagents. SS: designed research, collected data, wrote the paper.

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