

Long-term psychosocial outcomes after face transplantation: a patient's and a partner's perspective

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Abstract

To date, psychosocial outcomes after face transplantation are promising, although the impact on family relationships is less well investigated. Depressive and anxiety symptoms, resilience, spousal support, dyadic adjustment, family functioning of a patient and the partner were assessed before, and two, three and four years after the face transplantation. Most psychological, marital and family scores of both partners remained within a normative and healthy range at follow-up. Resilience, illness cognitions, physical quality of life, and family affective responsiveness and communication of the patient further improved, whereas the partner reported higher resilience and dyadic consensus at four years after transplantation. The results of this study point to positive long-term psychosocial outcomes of a blind patient and his partner after face transplantation.

Practitioner points

- Psychological health of patient and partner remains good after face transplantation
- Marital and family functioning remains stable after face transplantation and may even improve
- Face transplantation may strengthen the resilience of the patient and the partner

Keywords: face transplantation; psychosocial functioning; quality of life; dyadic adjustment; family functioning.

Introduction

Vascular composite allotransplantation (VCA) has gained increased acceptance in order to reconstruct complex facial defects in a one-stage procedure. To date, thirty-seven face transplants have been performed worldwide with encouraging immunological, functional, aesthetic outcomes (Coffman, 2015; Khalifian *et al.*, 2014; Roche *et al.*, 2015a; Sosin and Rodriguez, 2016). Despite many challenges, including rejection, immunosuppressive complications, extensive rehabilitation, media exposure, body image adaptation and social reintegration, most reports have indicated that face transplant patients show less depression, improved body image, better quality of life and good social (re)-integration (Khalifian *et al.*, 2014). However, quantitative data about psychosocial outcomes are rather scarce despite extensive pre-operative psychological and psychiatric assessment of all cases (Coffman, 2015; Khalifian *et al.*, 2014; Sosin and Rodriguez, 2016). Chang and Pomahac (2013) reported improvements in mental and physical quality of life of three facial transplant patients (of whom two had lost their eyesight) six months after surgery, while they had experienced a decline in their physical quality of life in the three months immediately after surgery. Self-esteem and dyadic function of the patients remained good. Another four patients showed large improvements in their quality of life, linked to the improvement in their facial function and appearance, one year after face transplantation (Lantieri *et al.*, 2011). However, long-term improvements in social integration and quality of life were highly variable among six face transplant patients and depended on pre-existing psychiatric comorbidities and social support (Lantieri *et al.*, 2016). Finally, depression and verbal abuse decreased, quality of life and societal reintegration of a legally blind, female patient improved up to three years after transplantation (Coffman *et al.*, 2010; Coffman and Siemionow, 2013).

Thus far, the impact of face transplantation on the psychological wellbeing of the family members or on couple and family relationships remains little investigated (Carty *et al.*, 2012). This is in contrast to several reports indicating that strong family and social networks (e.g. practical and emotional support from family, friends and community networks) not only buffer patients against transplant-related stressors (Arno *et al.*, 2012) but are also predictive of good post-transplantation outcomes (Soni *et al.*, 2010). As a result, inadequate social support is regarded as a psychosocial exclusion criterion for the face transplant candidate (Coffman, 2015). Thus far, only Lemmens and colleagues (2015) have examined the psychosocial outcomes of the partner of a blind face transplant patient. The partner showed no major depressive symptoms, hopelessness, and anxiety before and after the transplantation and at fifteen months follow-up. Moreover, she reported high resilience, good dyadic adjustment, and healthy family functioning on all assessments before and after the surgery. However, the marital support and depth as reported by the partner decreased at follow-up.

This article extends the latter study by reporting on the long-term psychosocial outcomes of the patient and his partner two, three and four years after transplantation.

Method

Participants and selection

A 54-year old male patient with a central facial defect after a ballistic injury and his female partner (52 years) participated in this study after giving their written informed consent. They have been married for more than 30 years and have several children. Digitally planned facial VCA was performed one year after the facial trauma. Details of the surgery, rehabilitation, postoperative course and outcome have been extensively described elsewhere (Lemmens *et al.*, 2015; Roche *et al.*, 2015b; Roche *et al.*, 2015b, 2015c; Van Lierde *et al.*, 2015). This study has been approved by the Ethics Committee of the Ghent University Hospital.

Assessment

Both the patient and his partner were asked to complete a battery of self-reports at baseline and two, three and four years after face transplantation. The baseline assessment, which was part of the screening protocol for face transplantation, took place three months after the facial trauma (Lemmens *et al.*, 2015). Further, the research protocol prescribed annual follow-up assessments up to five years after surgery. Psychosocial outcomes included subjective emotional health (SEH), severity of depressive symptoms (Beck Depression Inventory II; BDI-II), state and trait anxiety (Spielberger State Anxiety Inventory; STAI), hopelessness (Beck Hopelessness Scale; BHS), coping styles (Utrecht Coping List; UCL), resilience (Dutch Resilience Scale; RS-nl), family functioning (Family Assessment Device; FAD), marital adjustment (Dyadic Adjustment Scale; DAS) and spousal social support (Quality of Relationships Inventory; QRI). Illness cognitions (Illness Cognition Questionnaire; ICQ), quality of life (36-item Short Form Health Survey; SF-36) and psychiatric disorder (Mini International Neuropsychiatric interview; MINI, Dutch version 5.0.0, sections A to O) (Overbeek *et al.*, 1999) were assessed only in the patient. Because of the blindness, the patient was assisted in filling in the questionnaires by a member (e.g. psychiatrist) of the psychiatric team.

Measures

The BDI-II (Beck *et al.*, 1996; van der Does, 2002) is a 21-item self-report questionnaire assessing the severity of depressive symptoms: 0–13 (minimal), 14–19 (light), 20–28 (moderate) and 29–63 (severe). The BDI-II shows high internal consistency and test-retest validity.

The STAI (Spielberger, 1983; Van der Ploeg, 2000) is a 20-item self-report questionnaire assessing state and trait anxiety. Total scores vary from 20 to 80. For both state and trait anxiety, internal consistency is high. For trait anxiety, test-retest reliability is relatively high, whereas for state anxiety the stability coefficient tends to be low, as expected.

The BHS (Beck *et al.*, 1974) is a 20-item self-report questionnaire assessing twenty statements about the future that the subject rates as true or false. A score ≥ 9 indicates

levels of hopelessness associated with an increased risk of suicide. The scale has excellent internal consistency and test-retest reliability.

The DAS (Heene *et al.*, 2000; Spanier, 1976) is a 32-item self-report measuring relationship adjustment. Scores (below 100) represent significant relationship dissatisfaction or distress. It yields a total adjustment score and four subscores reflecting satisfaction, consensus, cohesion and affectional expression. Psychometric analyses support its test-retest reliability and validity.

The FAD (Epstein *et al.*, 1983; Maillette de Buy Wenniger *et al.*, 1993) is a 60-item measure assessing family functioning across seven dimensions: problem-solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning. A higher score on the FAD indicates *poorer* or *unhealthy* family functioning. The scale has good internal consistency and test-retest validity.

The QRI (Pierce *et al.*, 1991; Verhofstadt *et al.*, 2006) is a 25-item measure of spousal social support. The instrument includes three subscales: support, conflict and depth. The test-retest reliability and internal consistency are both satisfactory.

The RS-nl (Portzky *et al.*, 2010) is a 25-item measure assessing resilience. The instrument is scored on a 7-point Likert scale with a maximum score of 175. It has two components 'personal competence' and 'acceptance of self and life'. Test-retest reliability and internal consistency are satisfactory.

The UCL (Schreurs *et al.*, 1993) consists of seven subscales, with forty-seven items, measuring different coping styles in problem situations: active problem-solving, palliative reaction, avoidance, socialization, passive reaction, expression of emotions and reassuring thoughts. Internal consistency and test-retest reliability are satisfactory.

The SF-36 (Ware and Sherbourne, 1992) is a 36-item questionnaire consisting of a mental health (vitality, social functioning, role-emotional, and mental health) and a physical health (physical functioning, role-physical, bodily pain, and general health) component. The higher the summary scores, the better the quality of life. The SF-36 is a reliable and valid instrument.

The ICQ (Evers *et al.*, 2001) is an 18-item Dutch questionnaire measuring three generic illness cognitions that reflect different ways of re-evaluating the inherently aversive character of a chronic condition: acceptance ('a way to diminish the aversive meaning'), helplessness ('a way of emphasizing the aversive meaning of the disease') and disease benefits ('a way of adding a positive meaning to the disease'). Items are scored on a four-point scale with a maximum score of 24. Test-retest reliability and validity are satisfactory.

The SEH ('Subjective Emotional Health) is a 2-item measure assessing the current psychological and emotional state of one-self and the partner: 'How would you describe the current emotional and psychological condition of yourself/of your partner'. The items are rated on a 4-point Likert scale (1 = poor, 2 = not very good, 3 = quite good, 4 = very good).

Data analyses

The results of the patient and the partner were compared with available mean non-clinical population scores and/or cut-off scores of the questionnaires (Conner, 2010). Statistically reliable change index (RCI) for each scale was further calculated based on pre- and post-transplant scores: $RCI = (\text{post-test score} - \text{pre-test score}) / S_{diff}$. S_{diff} is the standard error of difference between the two test scores. An RCI above 1.96 is indicative of statistically reliable (positive or negative) change in N=1 designs (Jacobson and Truax, 1991). RCI of the ICQ was calculated on data from a rheumatoid arthritis patient population because normal control population data were lacking.

Results

Postoperative course

From the second year up to the fourth year after transplantation, the clinical situation of the patient remained unremarkable except for a recurrent pulmonary aspergilloma at month 31, which was treated with amfotericine B Ambisone IV (48 days) and Caspofungin IV (24 days) on an inpatient/outpatient base leading to full clinical recovery (Roche *et al.*, 2015b).

In the pre-transplant period, 12 psychiatric sessions and 44 psychological consultations (e.g. 17 individual patient sessions, 7 couple sessions and 14 family (member) sessions) were conducted. During the first 15 months after the transplantation, 35 psychiatric consultations (mainly with the partner), 4 family member sessions by the psychiatrist and 26 psychological sessions (e.g. 14 individual patient sessions, 8 couple sessions and 4 family (member) sessions) took place (see Lemmens *et al.*, 2015). During the second and third years post-transplant the psychological and psychiatric treatment was reduced to approximately a monthly psychiatric session (mainly with the partner and one with one of the children; 18 sessions/21months) and 12 psychological sessions (of which nine conjointly with the partner, one with the partner and two with the patient) and to four psychiatric and three psychological sessions (mainly with the partner and one with one of the children) during the fourth year post-transplant. The psychiatric sessions were conducted by a psychiatrist, who was also a senior family therapist. The psychiatric and psychological sessions followed no specific treatment protocol but focused on the psychological and physical health of both partners, the impact of the medical complications, the coping with the blindness, the social and family activities (including studies and work of the children), and the relational and family functioning of all family members.

Psychosocial outcomes at two, three and four years

The patient and the partner showed no major depressive symptoms, state and trait anxiety and hopelessness at two, three and four years follow-up (see Table 1). They rated their own emotional health as very good and their partner's from quite good (two years) to very good (three and four years).

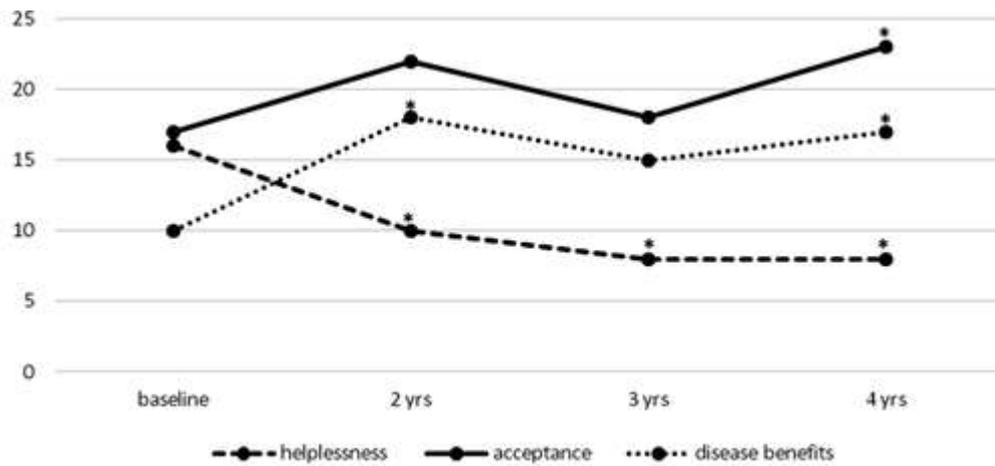
Table 1. Psychosocial functioning of patient and partner

	Baseline		2 years		3 years		4 years	
	IP	P	IP	P	IP	P	IP	P
SEH self	4	3	4	4	4	4	4	4
SEH partner	3	1	3	3	4	4	4	4
BDI-II	6	6	1	0	0	0	0	0
State anxiety	30	27	20	23	20	23	20	21
Trait anxiety	31	24	22	21	20	21	20	22
Hopelessness	4	5	0	1	0	4	0	3
Quality of life								
Physical health	60		95*		88,7*		92.5*	
Mental health	96.7		98.7		100		100	
Total	78.4		96.9		94,4		96.25	
Coping								
Active problem- solving	22	22	23	25	22	20	25	26
Palliative reaction	14	20	17	17	21*	20	18	18
Avoidance	12	17	16	18	15	18	16	14
Socialization	11	21	15	14	12	18	15	18
Passive reaction	10	7	7	8	7	10	7	7
Expression of emotions	3	3	4	6	4	4	4	4
Reassuring thoughts	9	12	13	13	16*	16	14*	15
Marital support								
Support	3.6	3.6	3.7	3.3	3.4	3.7	4	3.6
Conflict	1.5	1.2	1.8	1.0	1.7	1.3	1.9	1.4
Depth	3.8	3.8	3.8	3.3	3.8	3.2*	4	3.3
Family functioning								
Problem-solving	1.7	1.7	1.2	2.0	1.5	1.5	1.2	1.5
Communication	1.9	2	1.4	1.8	1.4	1.4	1.2*	1.5

	Baseline		2 years		3 years		4 years	
	IP	P	IP	P	IP	P	IP	P
Roles	1.3	1.2	1.3	1.4	1.2	1.3	1.1	1.1
Affective responsiveness	2.8	1.7	1.3*	1.3	1.7*	1.0	1.2*	1.0
Affective involvement	1.3	1.3	1.4	1.3	2	1.3	1.6	1.4
Behaviour control	1.2	1.2	1.1	1.2	1.2	1.0	1.1	1.0
Global functioning	1.3	1.4	1.1	1.5	1.2	1.3	1.0	1.1
Dyadic adjustment								
Affectional expression	12	10	12	12	12	11	12	11
Consensus	65	52	65	55	64	60	65	62*
Satisfaction	44	44	42	42	43	47	42	43
Cohesion	16	17	23*	17	20	18	16	20
Total	137	123	142	126	139	136	135	136

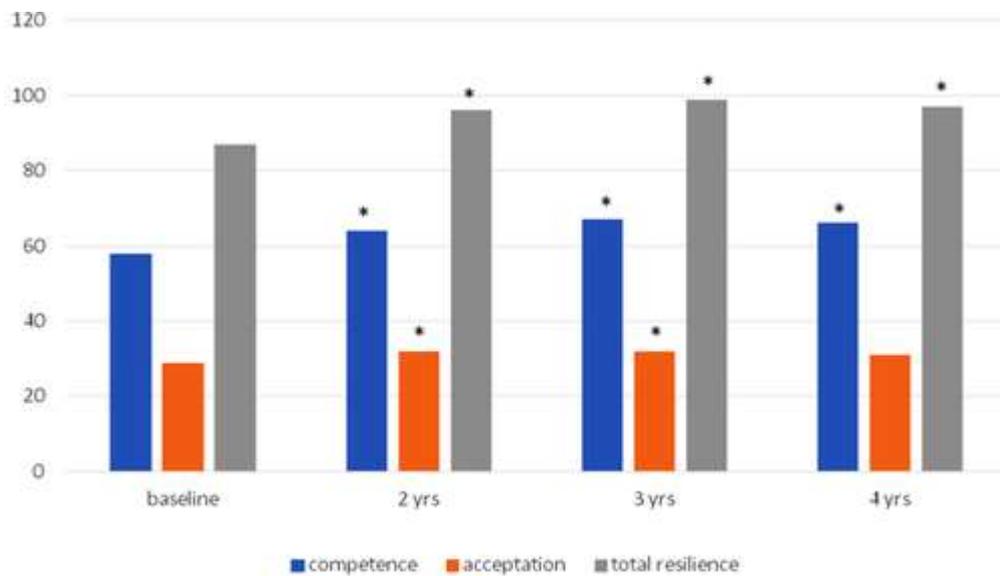
IP=patient, P=partner, SEH=subjective emotional health, BDI-II=Beck depression inventory-II, *=RCI>1.96.

Several psychosocial outcomes of the patient improved after transplantation. He felt less helpless (RCI: -2.2 (2 years), -2.9 (3 years) and -2.9 (4 years)), and reported more acceptance (RCI: 2.1 (4 years)) and disease benefits (RCI: 2.6 (2 years) and 2.3 (4 years)) (see Figure 1). His physical quality of health also strongly improved after transplantation (RCI: 8.7 (2 years), 7.2 (3 years) and 8.1 (4 years)). Further, he felt more resilient ((RCI: 2.5 (2 years), 3.4 (3 years) and 2.8 (4 years)), more personally competent (RCI: 2.3 (2 years), 3.5 (3 years) and 3.1 (4 years)) and more accepting of oneself and life (RCI: 2.1 (2 years) and 2.1 (3 years)) (see Figure 2). His coping style showed higher palliative reaction (RCI: 2.5 (3 years)) and reassuring thoughts ((RCI: 3.0 (3 years) and 2.1 (4 years)). The patient had already reported healthy marital and family functioning before the transplantation except for affective responsiveness, which improved after transplantation (RCI: -4.1 (2 years), -3.2 (3 years) and -4.5 (4 years)). Moreover, dyadic cohesion (RCI: 2.4) and family communication (RCI: -2.2) also improved at two and four years follow-up, respectively.



*=RCI>1.96

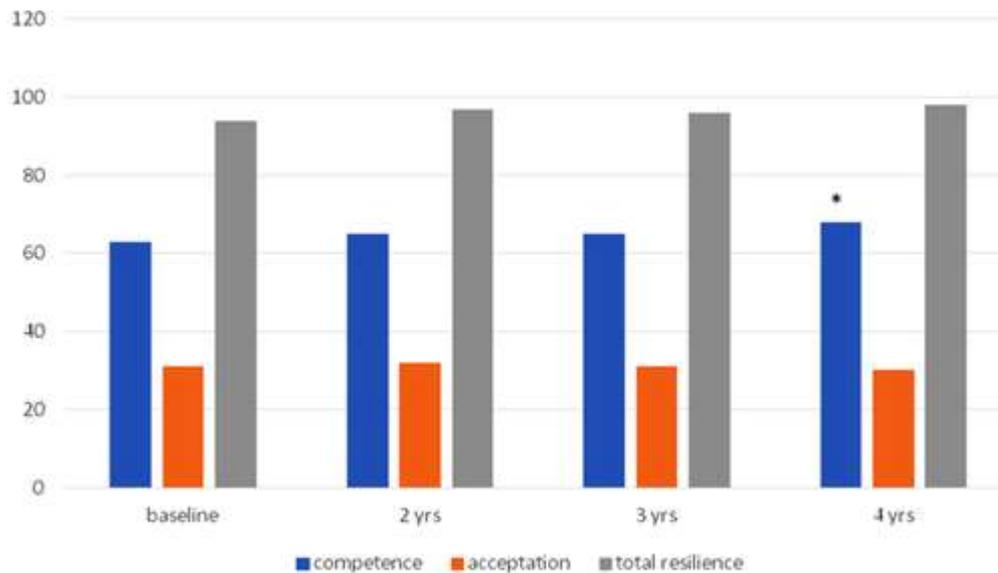
Figure 1. Illness cognitions of the patient.



*=RCI>1.96

Figure 2. Resilience of the patient.

No major changes were found in the partner's coping style after the transplantation. She reported higher personal competence (RCI: 2.0) at four years follow-up, despite the high baseline resilience scores (see Figure 3). Although total dyadic and global family functioning improved, only dyadic consensus (RCI: 2.1) became clinically significant at four years follow-up. However, she reported a decrease in marital depth (RCI: -2.0) at three years follow-up.



*=RCI>1.96

Figure 3. Resilience of the partner

Finally, MINI psychiatric interview of the patient showed at all assessments a lifetime, not current, depressive disorder. The patient had not been taking any antidepressant or psychotropic medication during the last 3.3 years.

Discussion

This study has investigated the long-term psychosocial outcomes of a blind patient and his partner two, three and four years after face transplantation. Overall, the psychosocial outcomes of both patient and partner have remained stable and good during this period. First, no important symptoms of depression, anxiety and hopelessness were reported by them. They both rated their own and their partner's sense of subjective emotional health as good to very good without any discrepancy between them. Further, the patient showed no psychiatric disorder at follow-up. These findings are not only in line with previous research indicating that face transplantation is well tolerated and psychologically beneficial for patients, even when they are blind, but they also add that these effects remain stable over a longer period after transplantation (Chang and Pomahac, 2013; Coffman *et al.*, 2010; Coffman and Siemionow, 2013; Khalifian *et al.*, 2014; Lemmens *et al.*, 2015; Roche *et al.*, 2015a). Further, they indicate that similar benefits may be found in the partners of face transplant patients. The partner in our study has not reported any psychologically distress from the transplantation (Lemmens *et al.*, 2015). It is likely that the good preoperative psychosocial stability of both partners, their high motivation and compliance with the treatment and rehabilitation programme and the good surgical outcome have contributed to these results (Diaz-Siso and Rodriguez, 2016; Lantieri *et al.*, 2016).

Secondly, important improvements were found in the physical quality of health of the patient at all three assessments points. This may partly be explained by the good recovery of most motor and sensory functions in the allograft, resulting in normal to only slightly diminished sensation on the right side, normal taste and smell, normal speech intelligibility and slightly impaired speech acceptability, normal swallowing and mastication (Roche *et al.*,

2015b). Further, the only postoperative complication that the patient had during this period was a pulmonary aspergilloma at 31 months post-transplant, which was treated clinically successfully within 72 days. This was in strong contrast with numerous severe medical complications mainly caused by the immunosuppressive treatment during the first 13 months after surgery (Lemmens *et al.*, 2015; Roche *et al.*, 2015c), strongly affecting his physical quality of health at the time.

Thirdly, the patient consistently experienced less helplessness, more acceptance and more positive meaning with respect to his chronic condition during the follow-up period. The successful surgery with good functional and aesthetic outcomes has probably contributed to these results. Further, the higher palliative and reassuring thoughts coping style, suggesting an accommodating rather than an assimilative coping style, may have benefited the patient living with a chronic condition (Poppe *et al.*, 2012). Finally, the high resilience of the patient before the transplantation with his proneness to feeling personally competent and easily accepting of himself and life, may have further helped him to feel less helpless and to create more positive meaning to his life. Moreover, it may also have strengthened his resilience over time. The latter process was also observed in the partner. Indeed, both partners became (even) more competent after the transplantation. Successfully overcoming the day-to-day difficulties associated with the transplantation, good social reintegration and adaptation to the blindness of the patient may have made them stronger persons. It is also likely that the partner felt more competent because she realized that she was able to deal successfully with the whole situation, including supporting the patient, during the post-transplantation period.

Fourthly, at the different follow-up assessments, the dyadic adjustment of both partners remained in a non-maritally distressed range (DAS>100) and their family functioning in a normative and healthy one. Even some aspects such as family communication, affective responsiveness and dyadic cohesion of the patient and dyadic consensus of the partner improved at some point. Our results support the findings of Chang and Pomahac (2013) showing no change in dyadic function up to six months after transplantation, especially when healthy marital and family functioning is already present before the surgery. On the contrary, the face transplantation may even more strengthen relationships. The strong involvement of the partner during the initial decision-making and the many medical visits and treatments after transplantation (such as the mainly conjoint psychological and psychiatric sessions) may also have supported their marital and family interactions. However, since the effect of the psychiatric and psychological help was not quantified, the question remains whether a couple in ordinary circumstances, provided with similar professional support, would expect to improve more than this couple. Our results may also underline the importance of good psychosocial support before the transplantation (Lantieri *et al.*, 2016) and the need for family involvement and support by the medical team after the transplantation (Lemmens *et al.*, 2015). Despite the high dyadic adjustment, the marital depth of the partner decreased at three years follow-up. A possible explanation could be that the patient, when he was struggling with the immunosuppressive complication (e.g. pulmonary aspergilloma), was periodically paying less attention to the needs of his partner (Lemmens *et al.*, 2015).

Limitations

Some limitations to the generalizability of the results need to be addressed. They include the small sample size, the relative short follow-up, the possible inclusion/selection bias and the selection of the measures. Further, no data were obtained from the children, who participated in some family sessions mainly in the pre-transplant period and during the first fifteen months after the transplantation.

Conclusion

The findings of this study support positive long-term psychosocial outcomes after facial transplantation, followed by a high level of input from qualified mental health professionals, not only for the patient but also for the partner.

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