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Quality of Life in Young Adults after Lung Transplantation: Only a Matter of Improved Performance?¹

Lung transplantation (LTx) is an established life saving measure in terminal lung disease. Apart from improved length of survival, the benefit of LTx is nowadays addressed regarding quality of life (QoL) [1]. The recent methodological discussion focusses on the pros and cons of generic vs. specific instruments to assess QoL [2]. Selecting the most suitable instrument according to the hypothesis in question may be one reasonable conclusion of this controversy [2,3] as may be the development of new instruments which combine generic and specific items in order to allow for comparisons between different patient populations, and to address disease specific aspects at the same time [4].

Both, generic as well as specific tools presuppose that the patient's personal frame of reference remains unaffected from his or her prior experiences. A pre to post assessment of QoL therefore is considered as reflecting the influence of a given intervention or experience on the individual's QoL. However, there are some "paradoxical" findings in QoL-research [5,2], namely that chronically ill patients tend to "overestimate" their QoL. These findings suggest that individual priorities regarding QoL are rather variable than fix. With respect to life threatening experiences such as LTx we wondered whether these would affect the individual's frame of reference, too. In other words: would this experience alter the recipient's perception of what constitutes quality in his or her life? And if certain components of quality of life would be more (or less) important, what does this mean with respect to common QoL assessments?

The present investigation was part of a larger study² on psychological aspects of LTx recipients (cystic fibrosis recipi-

ents versus recipients with other diseases) and regarding the experience of caregivers who supported these recipients during the acute transplantation period.

Method

To assess QoL we used all 19 items of the *Münchener Lebensqualitäts-Dimensionen-Liste* (Munich Life Dimension List; MLDL), but with a different response format and another instruction. The MLDL was developed on the ground of extensive semistructured interviews to explore a core set of "dimensions" or components, which usually constitute QoL.^[6] Each of the 19 items reflects a component of QoL and four domains (physical, psychological, social, daylife) may be calculated by summing up respective dimensions.^[7] We administered the MLDL with three different instructions: a) Have you experienced a change of *performance* on any of the dimensions since LTx? b) Is any of the dimensions more or less *important* since LTx? c) How *satisfied* are you with the respective dimensions at present? Responses were scored on a five-point scale (much improved, improved, unchanged, deteriorated, much deteriorated for instruction 1 and similarly for instruction 2; very satisfied "5" to very dissatisfied "1" for instruction 3).

Sample

We asked 66 lung transplant recipients to participate of whom 46 returned the questionnaires (age 19-42 years; mean

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age 39.1y). The majority of recipients (n=28) were cystic fibrosis patients; most of the other patients had interstitial lung disease (preselected for comparable age). Time since transplantation ranged from 1.1-10.9 years (median survival 5.6y; 1y survival requested minimum for participation). At the time of the study, 15 participants, all of whom had cystic fibrosis, still lived with their parents. 45 % of respondents were employed at least on a part time basis. 78 % of respondents had a couple relationship. Lung function at the time of the study was poor ($FEV_1 \leq 40$ % pred.) in 11 patients, 25 respondents had FEV_1 ranging from 41%-90% and 10 patients had $FEV_1 \geq 90$ %.

Results

Table 1 shows that there was a dramatic improvement of QoL after LTx in a number of dimensions. Also, there was a considerable shift towards greater perceived *importance* of several dimen-

sions of quality of life which is most pronounced for marriage/partnership, independence and physical functioning. Twelve of 17 recipients who reported that they now perceived independence as "much more important" also scored the optimum level of *satisfaction* on this dimension. Only one recipient in this group was apparently dissatisfied (level 1 of 5).

Results also indicate areas with rather low benefit: only 11% of recipients perceived success and reputation as substantially improved and similarly low rates were seen for financial and vocational situation, too. In contrast to dimensions which also showed low *improvement* but high current *satisfaction*, such as "friends", or feelings of "support and security", few recipients were satisfied with the current vocational or financial situation.

Conclusions

LTx not only leads to substantial improvements in QoL. Several components of QoL also become much more important indicating that the individual's frame of reference is rather variable than fix. At least for some dimensions, namely "physical functioning" and "independence", this shift of importance seems to be due to the dramatic improvement in performance after LTx, whereas the same shift of importance in "marriage/ partnership" rather appears to be influenced by developmental processes: there is improved importance without a substantial change in reality (performance).

To our impression, altered performance which coincides with a change of importance must be given more weight than a same improvement taking place on a lower level of individual importance. This should lead to a greater consideration of the individual's frame of reference in evaluating quality of life. This has now been established with a

Tab. 1: Percentage of recipients (n=46) who selected the best out of five levels of the respective item ("much"/"very") concerning perceived change since lung transplantation, altered importance and current satisfaction

QoL dimensions/ MLDL-Items	% of recipients reporting "much improvement" of the respective dimension	% of recipients reporting "much more importance" of the respective dimension	% of recipients who are "very satisfied" with the respective dimension
Physical domaine			
Overall health	73	33	48
Physical functioning	62	35	39
Mental functioning	13	22	41
Therapy	18	27	47
Coping with illness	11	20	33
Psychological domaine			
Personal well-being	56	30	39
Self-worth	31	20	33
Ability to relax	22	16	20
Success and reputation	11	4	16
Social domaine			
independence	56	37	48
vocational situation	23	7	16
financial situation	13	7	21
Housing situation	20	8	48
Leisure time	54	31	44
Daylife			
Feeling supported and secure	11	7	44
Marriage/partnership*	16	38	50
Sexual activity**	23	16	26
Family life	13	20	47
Friends	11	15	39

* 9 missing values; ** 6 missing values

questionnaire which systematically combines the patient's perceived importance with respective scores on performance^[8].

Furthermore, if it is right to interpret "paradoxical" QoL findings as revealing adaptation processes^[5], then the results of our study may well be interpreted as indicating the *reversible* nature of these processes. That is, recipients seem to *re-adapt* their aspirations to normal life. However, regarding such a re-adaptation there still remains "room for improvement", namely regarding the vocational and socio-economic situation (see table 1). This is in line with previous studies (e.g.^[9]) which also lead to the recommendation that transplant centres should offer career guidance to improve quality of life after transplantation^[10].

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Ethische Überzeugungen als Prädiktor des Organspendeverhaltens

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Bisherige Modelle der Organspendebereitschaft definieren Wissen über die Organspende, altruistische Wertorientierungen sowie Einstellungen gegenüber der Organspende als entscheidende Verhaltensdeterminanten. Demgegenüber erweisen sich in unseren Untersuchungen ethische Überzeugungen, die Totenruhe zu respektieren, als entscheidender Verhaltensprädiktor. Vorge stellt werden die Ergebnisse einer Studie (N = 730), in der neben Einstellungen gegenüber der Organspende ethische Überzeugungen zur Totenruhe sowie wahrgenommene moralische Verpflichtungen zur Organspende als Prädiktoren der Organspendebereitschaft erhoben wurden. Gemeinsam klären diese Prädiktoren 92% Varianz in der Organspendebereitschaft auf, wobei die ethischen Überzeugungen zur Totenruhe den stärksten Einfluss ausüben. Die Organspendebereitschaft ihrerseits erweist sich als guter Verhaltensprädiktor: Sie klärt 36% Varianz im Verhalten auf, Angehörigen den Wunsch zur Organspende mitzuteilen sowie 26% Varianz im Verhalten, einen Organspendeausweis auszufüllen. Der Zusammenhang zwischen der Spendenbereitschaft und tatsächlichem Verhalten wurde in der bisherigen Organspendeforschung kaum erfasst. Die Ergebnisse der Studie weisen darauf hin, ethische Überlegungen zur Totenruhe in der Organspendeforschung sowie in Kommunikationskampagnen zur Förderung der Organspendebereitschaft zu berücksichtigen.

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