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# Quality of life before and after liver transplantation: experiences with 7 patients with primary biliary cirrhosis in a 2-year follow-up

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**Abstract.** Seven patients with end-stage primary biliary cirrhosis were evaluated both before and 1 and 2 years after liver transplantation using a clinical psychiatric interview and the self-rating questionaire SCL-90. Neuropsychological tests were done before and 1 year after operation. Preoperatively, all patients had a poor general condition and overall quality of life. Flattening of emotions and reactions, regression, disturbances of verbal memory and cognitive function, and dependence on close relatives were observed. One year after transplantation, 6 patients had a much better overall quality of life, and with five patients it improved still further during the 2nd year, but only 2 patients felt that their life situation had fully stabilised. However, nearly all of them experienced phases of moderate or even severe depression or anxiety during those 2 years. On neuropsychological tests patients appeared to be near their normal level. The only patient who died during this follow-up (some months after transplantation) had in her life history a prominent sense of insecurity and mistrust. It seems to take more than a year for the majority of patients to give up the regressive mode of experience and turn to adult interests in life again, as well as psychologically experience the new liver as part of oneself.

**Key words:** Liver transplantation – Quality of life

The number of liver transplantations has increased and the long-term results have improved considerably in the past few years [9]. There is a growing need to know more of the patients' quality of life and about the long-term recovery process also from the psychological point of view. There are some studies dealing with psychiatric diagnosis [13] or neuropsychological complications [1] before or after liver transplantation and a few studies with a follow-up from before transplantation to some time after it [5, 11, 12] and only one with a multidimensional perspective to the recovery process including the quality of life [6, 7].

We describe in this study different aspects of the quality of life before and after liver transplantation on three main levels of human life: internal (both somatic and psychic), interpersonal, and functional level, which are all related to each other (Fig. 1).

## Materials and methods

We examined 7 adult patients with primary biliary cirrhosis (PBC) who were undergoing liver transplantation in Helsinki. There were 6 women and 1 man. Their mean age was 53 years, (range 45–64). They were evaluated both before and 1 and 2 years after liver transplantation by using a clinical psychiatric interview and a self-rating questionare. Neuropsychological evaluations were done before and 1 year after transplantation. Preoperative evaluations were performed just after the decision of transplantation had been made and the patients put on the waiting list.

The psychiatric interview was semistructured so that the same topics were discussed with every patient, starting from the present life situation and the course of their illness to the coming operation and the future, with special interest in their fears, hopes, and fantasies and their relationship to their family and other people near them. The basic sense of security or insecurity and the ways with which they had reacted to stressful situations or big losses in the past were estimated from their life history.

As a self-rating questionare we used the SCL-90 [3]. It is a 90-item symptom checklist with 9 primary symptom dimensions and 3 global indices of distress. Each item is rated on a 5-point scsale ranging from Not-at-all at one pole to Extremely at the other.

The neuropsychological evaluation was done before and 1 year after transplantation using the following methods [8]: Wechsler Adult Intelligence Scale (WAIS), Wechsler Memory Scale (WMS), trail making test for visuomotor tracking, Stroop test for capacity to resist mental interference.

The neuropsychological findings were compared with a reference group of 53 healthy Finnish males aged 41–50 years. Two patients were retransplanted some months after the first transplantation and their follow-up evaluations were done 1 and 2 years after the second transplantation.

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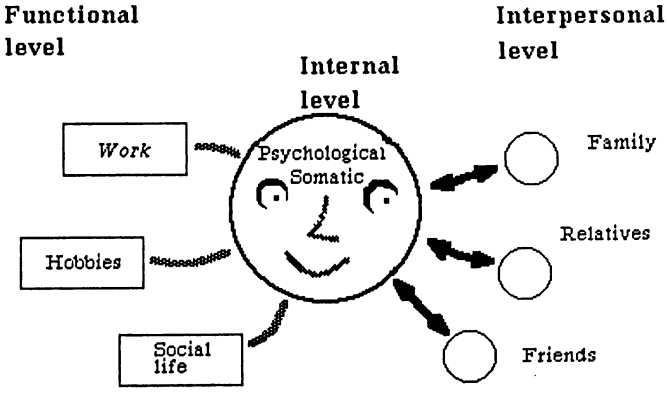


**Fig. 1.** Different levels of quality of life

## Results

Before transplantation all patients were in a poor general somatic condition; they were tired, muscle wasting was evident, most of them had ascites and had had variceal bleedings. None of them was able to work anymore, and they had all moderate to severe difficulties in daily functioning. General flattening of emotions and reactions was evident with every patient when compared with the way they reacted and described their feelings and life situations in the follow-up evaluations. They needed a lot of help and felt dependent on either their family and close relatives or hospital staff. Two of the patients felt insecure, and they did not receive much support or understanding at home. One of them was the only patient who died during this follow-up (some months after transplantation). The rest of the patients found support from family and relatives very important and helpful.

One year after transplantation, all 6 patients had a clearly better somatic condition, although they all experienced various somatic complications during that year. Also, every patient had a much better general functional ability. Four patients were able to work somehow in or outside home and had picked up some hobby. Two patients still seemed to need quite a lot of help at home. All patients felt that their functional ability became even better during the 2nd year; they were all able to do duties at home almost normally, they felt more independent and had interests and hobbies of their own. Two patients had a cataract that somewhat restricted their functioning.

The neuropsychological tests showed some impairment in intelligence (WAIS) and in memory (WMS) before transplantation in every patient (Table 1). These impairments improved to the expected level 1 year after transplantation. Visuoconstructive apraxia was more marked in all these patients before transplantation, and some impairment still remained in the mental flexibility of 5 patients 1 year after it.

The results of SCL-90 (Table 2) showed as a general tendency that all successfully transplanted patients were feeling better 1 year after transplantation; they had fewer somatic complaints, they were less depressed and anxious and less sensitive in their relationships with other people than before transplantation. After 2 years the scores were even better. During the 1st year, the interviews revealed phases of moderate or even severe depression in 5 patients and general anxiety or anxiety attacks in 4 patients. During the 2nd year 2 patients had a phase of depression, and 3 still felt anxiety, although less severely than during the 1st year. With 1 patient the depression was long lasting, and her condition worsened during the 2nd year. These difficulties were often related to somatic complications, occasionally to a family problem, but also to inner psychic conflicts and fears.

## Discussion

Different organ transplantations have common features from the psychological point of view [10]. Liver transplantation has though its specific features, with hepatic encephalopathy and neurological symptoms [1, 12] that influence all levels of the quality of life.

On the functional level there was much improvement from the preoperative situation in which all patients needed help in everyday life to the point where they all managed quite well in normal daily duties and interests in adult life. Nevertheless, most of these patients felt after 2 years that some of their life energy was still missing.

On the interpersonal level, support from family and other relatives seemed to be most important as has been noticed in several studies before [2, 7]. The general sense of security and ability to be helpless without shame seemed to support the recovery from transplantation. In this study, insecurity and lack of family support were related to a poor outcome. This could be a risk factor, and an extra effort should be made to offer such patients more support.

In this group of patients there was less impairment in intelligence and memory tests and more visuomotor apraxia than was found in another group of patients ($n = 8$) tested with the same methods [5].

On the psychological level, varying degrees of depression and anxiety were observed in every patient sometime during these 2 years. A self-rating questionnaire did not

**Table 1.** Neuropsychological test results before and after transplantation

| | Before transplant ($n = 7$) | After transplant ($n = 6$) | Controls ($n = 53$) |
|---|---|---|---|
| Wechsler Adult Intelligence Scale | | | |
| VS | 106 ± 12.3 | 111 ± 10.7 | 110 ± 13.3 |
| PS | 98 ± 14.3 | 108 ± 10.0 | 109 ± 12.9 |
| Wechsler Memory | 106 ± 20.1 | 120 ± 20.2 | 118 ± 15.6 |
| Stroop C Scale | 172 ± 28.7 | 115 ± 20.3 | 110 ± 24.6 |
| Trail B | 157 ± 52.1 | 132 ± 54.0 | 101 ± 46.0 |

Mean ± SD

**Table 2.** SCL-90 results before and after transplantation

| | Before Transplant | 1 year after | 2 years after |
|---|---|---|---|
| Somatization | 64 ± 3.6 | 58 ± 9.8 | 54 ± 10.8 |
| Depression | 64 ± 7.3 | 54 ± 9.8 | 52 ± 4.3 |
| Anxiety | 61 ± 6.0 | 56 ± 8.2 | 48 ± 7.4 |
| Interpersonal sensitivity | 61 ± 8.2 | 53 ± 9.7 | 48 ± 8.9 |
| Global severity index | 65 ± 4.2 | 58 ± 6.1 | 52 ± 6.5 |

reveal these individual variations well. There seemed to be a general tendency of denying symptoms and difficulties in the questionnaire, compared with what these patients said in the interviews. The same observation was made by Heyink et al. in their study [4]. Many of these patients seemed to need denial before transplantation as a psychological defence mechanism. Under such extreme circumstances, denial can be helpful in dealing with overwhelming emotions. Also, the drowsiness and flattening of emotions caused by hepatic encephalopathy could be a shelter from overly strong emotions. Several patients found their sense of humor to be important in this recovery process.

We describe in this study different aspects of the quality of life from the experience of 7 patients before and after liver transplantation. There is a great individual variation in the psychological recovery process. Although all successfully transplanted patients already feel much better 1 year after transplantation, it seems to take about 2 years for them to stabilise the new life situation.

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