

# Do retrospective and prospective quality of life assessments differ for pancreas-kidney transplant recipients?

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**Abstract** The literature indicates that chronically ill patients have a remarkable capacity to adapt to their illness. For example, they will generally report a better quality of life (QoL) than individuals in the general population who are asked to imagine themselves as chronically ill and to rate their QoL. The present study further explores this phenomenon in type I diabetic transplant recipients with end-stage renal disease. In a prospective, longitudinal study, we assessed the QoL in 22 patients, both before and after they received a combined pancreas-kidney transplant. After transplantation, the patients were also asked to assess their pretransplant QoL by rating it on a 10-point scale. What we found was that prior to transplantation, QoL was prospectively given a mean rating of 5.23; this score increased to 7 after a successful transplant procedure. During follow-up assessments 5, 12, and 18 months after successful transplantation, patients retrospectively scored their pretransplant QoL as 3.27, 3.14, and

3.05, respectively. We conclude that when type I diabetic patients with end-stage renal disease undergo a transplant procedure to improve their health status, they re-evaluate their pretransplant QoL, and this retrospective assessment is significantly lower than their prospective one when transplantation is successful.

**Key words** Quality of life measurement, pancreas-kidney transplantation, adaptation · Pancreas-kidney transplantation, quality of life measurement, adaptation

### Introduction

In the past few years, "quality of life" (QoL) has attracted considerable attention as an outcome parameter in clinical research [10]. One reason is the increased prevalence of chronic diseases in an aging society [4]. For these diseases, the goal of medical interventions is not to cure, but rather to improve the well-being of patients.

Not surprisingly then, in both clinical decisions and policy-making, there is a need to assess health-related QoL in an accurate way [1].

Gill and Feinstein claim that QoL is a unique, personal perception denoting the way that individual patients feel about their health status and/or nonmedical aspects of their lives [12]. Calman describes QoL as a dimension that can only be measured in individual terms

and that depends on present lifestyle, experience, hopes for the future, dreams, and ambitions [7]. With a modest level of expectations, acceptable subjective well-being is possible, even in objectively awkward circumstances [7]. Good QoL can be said to be present when the ambitions of an individual are matched and fulfilled by experience [7]. The fact that chronically ill patients adapt to their illness may affect QoL assessments. For example, Cassileth et al. [8] found that five groups of physically ill patients (suffering from arthritis, diabetes, cancer, renal disease, and dermatologic disorders) did not differ significantly from one another or from the general population in terms of their mental health scores (e.g., anxiety, depression, general positive affect, emotional ties, loss of control, or mental health index). O'Boyle et al. found results that suggest that adaptability and previous experience can substantially modify perception of QoL [20].

Adaptation can be described as a process in which past, present, and future circumstances are interpreted or evaluated in such a way that an acceptable level of well-being is achieved. It is assumed that certain events and situations can, indeed, seriously compromise the subjective feeling of well-being. However, adaptation usually takes place in due course, resulting in a level of well-being "belonging to the person" [15]. Dramatic events in the past or a decline in an individual's physical condition does not necessarily result in a reduced subjective well-being [19]. Furthermore, current problems can be put into perspective by referring to periods during which the person was worse off. Another strategy for assessing one's own situation positively is to compare oneself with others who appear to be in a more difficult situation. This phenomenon is called "downward social comparison" [21]. It is known that all people tend to believe that their future will be better than their present or their past [6]. In addition, some people greatly exaggerate the likelihood of positive outcomes in the future and judge their own outcomes as less likely than others to be negative [23]. These "positive illusions" illustrate a number of adaptive strategies and mechanisms that individuals tend to apply to restore well-being. It is plausible to assume that the relationship between adaptation and well-being is reciprocal: when a person's feeling of well-being is undermined, adaptive means are mobilized, which subsequently contribute to recuperation [15]. Heyink gives a more detailed overview of the strategies individuals use to overcome misfortune and to restore their subjective well-being [15]. He reports that chronically ill patients have a remarkable capacity to adapt to their illness and will generally report a better QoL than individuals in the general population who are asked to imagine themselves under conditions of chronic illness and to rate their QoL. In fact, Tsevat et al. found that self-reported QoL of seriously ill patients is higher (i.e., better) than the patients' proxies (e.g., family members) believe them to be [22]. Fur-

thermore, these authors also found that QoL changes with time and, under normal circumstances, can change considerably.

The current study explores changes in QoL ratings in pancreas-kidney transplant recipients. More specifically, we investigated whether these chronically ill patients who underwent an intervention to improve their health status, in fact retrospectively lowered their pre-intervention QoL ratings. Such a pattern of QoL ratings indicates that this sort of assessment reflects adaptive processes. It also implies that retrospective QoL scores are unreliable, precisely because they underestimate the capacity of chronically ill patients to adapt to their illness.

### Patients and methods

A prospective, longitudinal, multicenter study was performed to assess the QoL of 22 patients with type I diabetes and end-stage renal disease, both before and after they received a combined pancreas-kidney transplant that functioned for at least 5 months post-transplantation [2]. In addition, patients were asked post-transplantation to evaluate their pretransplant QoL. The study was from June 1992 to January 1994. In this study a successful transplant procedure was defined as one that resulted in kidneys and pancreas functioning properly ( $n = 17$ ) or in the patient being rejected soon after the transplantation ( $n = 5$ ).

The present study was part of a larger research project on patient evaluation [2, 3]. This project was approved by the ethics committee. All patients gave their informed consent prior to their inclusion in the study.

The patients were interviewed at their homes prior to transplantation (baseline) and at 5, 12, and 18 months post-transplantation. Each time they were asked to assess their current QoL using it on a 10-point visual analogue scale (VAS) on which "1" represented "worst imaginable QoL" and "10" "best imaginable QoL". During the three post-transplant follow-ups, the patients were asked to estimate their pretransplant QoL.

There were several reasons for choosing to use VAS as an index of QoL, among them the fact that a VAS is easy to understand and requires very little time. Moreover, according to Gill and Kane [11], VAS ratings are one of the most promising instruments in terms of reliability, validity, and feasibility. In addition, VAS ratings are widely used in QoL research [11, 12].

In the current study, the QoL assessment (i.e., the VAS) was introduced to patients as a subjective way of assessing one's health. To examine to what extent QoL ratings are related to general well-being and future expectations, patients were asked to complete the Affect Balance Scale (ABS) [5, 9] and to answer a question about these future expectations.

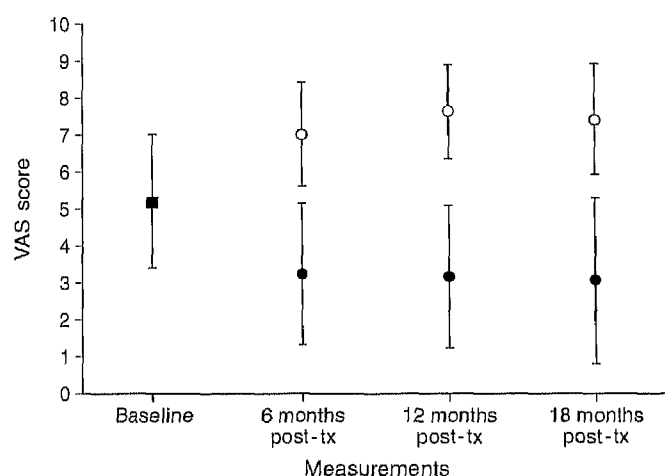
The ABS was chosen because it yields an overall score that is a good index of general well-being [2, 5, 9]. Furthermore, according to Gill and Feinstein, the ABS is an available indicator of well-being when it is applied along with a subjective rating scale, similar to the VAS in the present study [12]. The ABS questionnaire includes ten questions about positive and negative affects that are evaluated in terms of absence or presence ("1"). Interpretation of the ABS score is as follows: a score below 2 indicates general well-being that is less than average, a score of 2 is average, and a score above 2 is above average [9]. In this study, a validated form of a Dutch version of the ABS was used [9]. The prospective VAS and ABS scores (

**Table 1** Mean VAS scores and standard deviations (SD) pre- and post-transplantation

Assessment of current QoL	Mean	SD
Pretransplantation (baseline)	5.23	1.82
At 5 months post-transplantation	7.05*	1.40
At 12 months post-transplantation	7.62*	1.28
At 18 months post-transplantation	7.40*	1.50
Retrospective assessment of pretransplant QoL		
At 5 months post-transplantation	3.27**	1.91
At 12 months post-transplantation	3.14**	1.93
At 18 months post-transplantation	3.05**	2.24

\*  $P < 0.000$  (significant increase; within measurements,  $df = 57$ , 14.94);

\*\*  $P < 0.000$  (significant decrease; within measurements,  $df = 57$ , 14.27)



**Fig. 1** Prospective and retrospective VAS scores presented as means and standard deviations. ● Retrospective; ○ prospective

5, 12, and 18 months after transplantation) were expected to correlate positively [12]. However, when patients retrospectively assess their baseline QoL differently after an intervention, these retrospective scores do not generally correlate with the baseline ABS score. During baseline and prospective assessments, patients were also asked "When you consider the future, what state do you expect your health to be in 1 year from now?" in order to examine whether future expectations affect retrospective and prospective QoL assessments.

VAS scores were tested for normality with a Kolmogorov-Smirnov test. Data were expressed as means and standard deviations (SD). A repeated-measures ANOVA (within measurements) was used to test the null hypothesis that pretreatment QoL ratings do not differ from retrospective, post-treatment ratings. Conservative criteria for statistical significance were applied, and standard Bonferroni correction was used. The null hypothesis (i.e., that the three retrospective, post-treatment VAS scores would not differ from each other) was tested using the same approach. Finally, we examined whether prospective QoL assessment was higher post-transplantation. Due to their ordinal character, differences in patients' expectations over the time were tested nonparametrically with a Wilcoxon matched-pairs signed rank test. The correlation

between VAS and ABS was investigated by calculating Pearson correlations. Data were analyzed with SPSS, version 6.1.

## Results

Two patients with a pancreas and kidney functioning at 5 months post-transplantation were not able to finish the study. One patient suffered from a stroke and could not be interviewed after 12 months, and the other died before 18 months had passed. Overall, VAS scores had a normal distribution. Table 1 shows the mean VAS scores pre- and post-transplantation. The QoL on the VAS was prospectively assessed as 5.23 at baseline and increased significantly to over 7 after successful transplantation ( $P < 0.001$ ; Table 1, Fig. 1). At 5, 12, and 18 months after successful transplantation, patients retrospectively assessed their pretransplant QoL as 3.27, 3.14, and 3.05, respectively (Table 1, Fig. 1). On the basis of these data, the null hypothesis could be rejected ( $P < 0.001$ ). Parameter estimation showed a strong linear trend (coefficient =  $-1.755$ ,  $t = 4.803$ ;  $P < 0.001$ ). The three retrospective post-transplant ratings did not differ significantly from each other ( $P = 0.405$ ; Table 1) [3].

The retrospectively assessed baseline VAS scores did not correlate with the baseline ABS score ( $r_{5 \text{ months}} = -0.076$ ,  $r_{12 \text{ months}} = -0.113$ ,  $r_{18 \text{ months}} = -0.100$ ). The prospective VAS scores correlated moderately with the ABS scores [ $r_{\text{baseline}} = 0.297$ ,  $r_{5 \text{ months}} = 0.575$  ( $P < 0.01$ );  $r_{12 \text{ months}} = 0.484$  ( $P < 0.05$ ); and  $r_{18 \text{ months}} = 0.477$  ( $P < 0.05$ )]. Patients' ABS scores increased from 2 at baseline to 3.5 after transplantation, although this improvement was not significant ( $P = 0.1579$ ). Patients' expectations with regard to their future health (Table 2) changed significantly over time [Wilcoxon matched-pairs signed rank test;  $Z = -2.4962$  (12 months) and  $Z = -2.3094$  (18 months,  $P < 0.05$ )], with 59.1% of them believing in improvement before transplantation and 35% believing in improvement at 12 and 18 months after transplantation. Table 2 suggests that the data are similar for baseline and 5 months, and similar for 12 and 18 months, with the latter two measurements differing from the former two measurements.

## Discussion

The most important finding of the present study is that prospective QoL assessments differ considerably from those made retrospectively. Patients who underwent a successful transplant procedure underestimated their previous self-reported baseline QoL score. From a psychometric perspective, this finding underlines the critical difference between QoL ratings pertaining to the current situation and those pertaining to a previous period.

**Table 2** Patients' expectations regarding the state of their future health. *Question:* "When you consider the future, what do you expect your health to be like in 1 year?"

Point in time	Pretrans-plantation	5 Months post-trans-plantation	12 Months post-trans-plantation	18 Months post-trans-plantation
<i>Answer: I expect it to:</i>				
improve	13 (59.1 %)	14 (63.6 %)	8 (38.1 %)	6 (30 %)
remain the same	5 (22.7 %)	5 (22.7 %)	12 (57.1 %)	13 (65 %)
worsen	0	0	0	0
I cannot tell	4 (18.2 %)	3 (13.6 %)	1 (4.5 %)	1 (5 %)

Data expressed as absolute numbers and (percentages)

One could question whether a difference of about two points (i.e., the difference between 5.23 and 3.05) on the VAS is a clinically relevant difference. When one considers that two points on the VAS represents the difference between being on dialysis or having a perfectly healthy kidney and, in most cases, a functioning pancreas (i.e., the difference between 5.23 and 7.62), one should conclude that a two-point difference on the VAS is, indeed, very clinically relevant [2]. However, it should be noted that this is only true when the VAS is at least interval-scaled, which is assumed.

From these findings, one may conclude that studies that retrospectively assess QoL in chronically ill patients lead to different conclusions than studies based on prospective assessments of QoL. A likely explanation for this phenomenon is adaptation to illness during the pre-transplant period [3]. It is reasonable to assume that patients' expectations regarding the state of their health at baseline were heightened because of the prospect of a cure for both nephropathy and diabetes. Thus, one could argue that expectations about one's future health influence the baseline QoL score. Yet, there appears to be little or no difference with regard to these future expectations between the pretreatment and 5-month post-treatment evaluations, even though the QoL scores differ. Presumably, this difference in VAS score is related to a change in health status and not to future expectations. In addition, serial QoL assessments after transplantation do not seem to reflect any dramatic changes in future expectations about the state of the patients' health (Tables 1, 2). As stated earlier, adaptation refers to strategies that individuals use to overcome misfortune and to restore their subjective well-being. A shift in one or several of these strategies will change the perceived, retrospective QoL after transplantation. If, due to the transplantation, a patient's attitude towards the adaptive strategies changes, the patient's assessment of his QoL cannot be interpreted properly. This is because the post-transplantation patient operates as a differently calibrated person with regard to adaptational strategies. This response shift [15], rather than future expectations

or well-being, provides an explanation for the difference between current and retrospective assessments of QoL.

Kiebert et al. [17] used the VAS in a retrospective, cross-sectional study with a similar patient group (type I diabetic patients with end-stage renal disease). They found that, after an unsuccessful transplantation (rejection of both pancreas and kidney), patients tend to retrospectively upgrade their perception of their QoL before transplantation. In contrast, the present results show that, after a successful transplantation, patients underestimate their baseline QoL. Thus, it seems that variations in QoL are outcome-dependent.

Several studies have assessed the ability of respondents to recall their state of health when the same individuals are asked identical questions at a later time [14, 16, 18]. Herrmann [14] acknowledged recall bias as a possible distortion factor in retrospective designs. Forward et al. [15] have referred to this re-evaluation as a retrospective pretest, and to the re-evaluation as a response-shift effect. The sample in which they investigated this phenomenon was one consisting of undergraduate students and not of chronically ill patients. For this reason, the results of their study are difficult to generalize to the present context. Mancuso and Charlson [16] found results similar to those in our study. Their patients had undergone total hip replacement, but the effect was interpreted as recall bias. Mancuso and Charlson [16] sought to determine whether there were systematic biases to the disagreement between actual and recalled status. Their results showed that there were differences in the number of patients who had recollection errors for the different domains. No trend of systematic bias was found, and the magnitudes of the biases were the same within a sub-group. This contradicts our findings, in which parameter estimation showed a strong near trend of systematic bias and a small standard deviation of the results within the study group. Adaptation rather than recall bias, is a plausible explanation for the results of the present study.

Recently, Guadagnoli and Cleary [13] concluded that a change in one's health does not depend upon whether a baseline assessment was recalled or made prior to intervention. These results are difficult to reconcile with the present results. However, one must be reminded that Guadagnoli and Cleary were studying patients with acute myocardial infarction, whereas the present study involved chronically ill, insulin-dependent patients with end-stage renal disease. Patients with end-stage renal disease are worried about their well-being, but as time goes by, this impaired well-being leads to a decrease in the patients' internal standard against which the disease is evaluated [20]. In other words, time is a great healer. Thus, one cannot expect acute patients and chronically ill patients to adapt in the same way. Mancuso and Charlson's findings [18] underline this fact.

Finally, it should be pointed out that this study suffers from a few methodological limitations. The sample size is small, due to a highly specialized nature of the intervention, which is not often carried out, and the fact that few patients met the inclusion criteria for the procedure. Because of this small sample size, a conservative statistical approach towards significance was used. It should also be noted that a patient's ability to recall prior functioning can vary, depending on the type of scale employed. In this study, only a VAS was used to assess the QoL. It should be emphasized that the VAS is a subjective, single-index measure incorporating all aspects of QoL from a specific patient's point of view. With a VAS one cannot distinguish between certain specific do-

main of QoL, such as social and emotional functioning, and symptoms.

Nevertheless, these limitations do not invalidate the conclusion that can be drawn from the current results, namely, that retrospective QoL assessment does not reflect the patient's subjective state to which retrospective measurements refer.

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