

Overall recovery after stroke: a patient's perspective

Masterthesis

Physiotherapy Science

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“ONDERGETEKENDE

Marloes Steenhuisen,

bevestigt hierbij dat de onderhavige verhandeling mag worden geraadpleegd en vrij mag worden gefotokopieerd. Bij het citeren moet steeds de titel en de auteur van de verhandeling worden vermeld.”

Examiner

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SAMENVATTING

Doelstelling

Het doel van deze studie is om het herstel dat de patiënt ervaart na een beroerte in kaart te brengen, factoren te zoeken die gerelateerd zijn aan de mate van het ervaren herstel en patiënten te identificeren die vooruitgang laten zien op zowel subjectieve als objectieve uitkomstmaten.

Methode

Dit onderzoek wordt gedaan binnen de bestaande dataset van de FITstroke studie. De Stroke Impact Scale werd gebruikt om het ervaren herstel in kaart te brengen, dit was de primaire uitkomstmaat van deze studie. Andere uitkomstmaten die zijn meegenomen zijn: loopvaardigheid, balans, perifere spierkracht, depressie en angst, kwaliteit van leven en vermoeidheid. Om de factoren die gerelateerd zijn aan het ervaren herstel in kaart te brengen werd een regressie analyse uitgevoerd. De data werd gedicotomiseerd aan de hand van in de literatuur gevonden afkapwaarden om de patiënten te kunnen identificeren die een verandering lieten zien op zowel de subjectieve als de objectieve uitkomstmaten.

Resultaten

Honderdzesenzeventig (60.6%) patiënten gaven een vooruitgang aan in ervaren herstel na de beroerte gedurende de poliklinische revalidatie. De loopvaardigheid, perifere spierkracht, depressie en angst, kwaliteit van leven en vermoeidheid blijken significant gerelateerd te zijn aan het ervaren herstel na een beroerte. Er werd een significante associatie gevonden tussen loopvaardigheid en het ervaren herstel na een beroerte.

Conclusie

Een groot aantal patiënten liet een toename zien in het ervaren herstel tijdens de poliklinische revalidatie. Er werden verschillende factoren gevonden die gerelateerd zijn aan het ervaren herstel na een beroerte maar niet alle variantie kon in het uiteindelijke model worden verklaard. Verwacht wordt dat er nog andere factoren gerelateerd zijn aan het ervaren herstel dat een patiënt aangeeft na een beroerte die in deze studie niet werden gevonden.

Klinische relevantie

Veranderingen in functioneren tijdens en na de revalidatie worden vaak in kaart gebracht door het gebruik van objectieve meetinstrumenten. Het is niet duidelijk of de veranderingen die dan worden opgemerkt ook zo belangrijk zijn vanuit het perspectief van de patiënt, behalve voor loopvaardigheid. Om de patiënt meer centraal te laten staan in de behandeling kunnen de factoren die gerelateerd zijn aan het ervaren herstel gebruikt worden om doelen te stellen en evalueren tijdens de revalidatie.

ABSTRACT

Aim

The aim of this study is to describe changes in patient perceived recovery during outpatient rehabilitation, identify factors related to the patient perceived overall recovery and identify patients showing improvement on both subjective and objective measures.

Methods

This is a secondary analysis with patients recruited for the FITstroke study.

The primary outcome of this study is the patient perceived overall recovery which was measured using the Stroke Impact Scale. Secondary outcome measures included walking ability, balance, peripheral muscle strength, depression and anxiety, quality of life and fatigue. To find factors related to patient perceived overall recovery a regression analysis was performed. Data was dichotomized using cut-off points found in literature to identify patients showing improvement on both subjective and objective measure.

Results

One hundred and sixty-four (60.6%) experienced an increased perceived overall recovery during outpatient rehabilitation. Walking ability, depression and anxiety, quality of life and fatigue were found to be significantly related to the patient perceived overall recovery. A significant association was found between walking ability and the patient perceived overall recovery.

Conclusion

The majority of the patients experienced an increase in patient perceived overall recovery during outpatient rehabilitation. Several factors were found to be related to the patient perceived recovery but the final model could not explain all of the variance. It is assumed that several other factors are also related to the patient perceived overall recovery which could not be identified yet.

Clinical Relevance

Improvements in function during and after the rehabilitation are often identified by changes in performance on assessment instruments. However based on the results of this study, except for walking ability, it is not clear if those identified changes are also important from the patient's perspective. To facilitate a more patient-centered approach, factors found to be related could be used in rehabilitation for setting and evaluating goals.

Keywords:

Patient perceived recovery, Stroke impact scale, patients perspective, subjective outcome measure, objective outcome measure

INTRODUCTION

Background

Stroke is a major health problem and a leading cause of death and disability in many western countries.(1,2) The incidence of stroke is high, in the Netherlands nearly 46.000 people are affected with stroke each year. Based on demographic trends it is expected that the absolute number of patients with stroke will increase with 56% for men and 37% for women between 2011 and 2030.(3) The effects of stroke are wide-ranging on physical, mental and social life domains.(4) Because of the societal burden posed by stroke, better strategies to deliver efficient and effective care are still needed.(5)

The most common impairment caused by stroke is motor impairment (6), it is seen in 80% of the patients and affects the functioning of leg, arm and face on one side of the body.(7) More than 30% of the patients with stroke is not able to walk independently after six months, having a great impact on performing activities of daily living.(8) Early multidisciplinary stroke rehabilitation is initiated to achieve optimal recovery. Improvement of walking function and the recovery of balance and movement is the most commonly heard therapy goal in stroke rehabilitation.(9,10) In the end, the rehabilitation should result in a better quality of life and degree of participation in the community.(11) Social participation is independently associated with health related quality of life in early and late phases of stroke recovery.(12,13) Baseman et al. found that individual's perception of total perceived recovery is a significant predictor of social integration after stroke. (14)

At this moment, improvements during rehabilitation are often assessed by changes on objective performance based measures. These changes may demonstrate results that are statistically significant but the clinical importance of these significant changes is not always clear.(15) Lately, policy makers are facilitating an approach where the perception of the patient is becoming more and more important. For example, The Royal Dutch Society for Physical Therapy (KNGF) recommended a patient-centered approach in their recently revised guideline for stroke.(16) Porter and Lee proposed a strategy for improving the quality of care involving measuring value-based health care given to patients where value can be defined as the total benefit gained by a patient relative to the costs of obtaining that benefit.(5) Patient's perspective could differ from the practitioner's perspective or from the changes measured on performance based measurements and therefore could be very important in assessing the effectiveness of the treatment. Patient's perspective could even be used to determine the clinically important differences. Lastly, the patient is deciding whether the treatment has worked.(17)

Objectives

Most effects of stroke rehabilitation are assessed using objective performance based measures. None of the objective outcome measures have been compared with an external criterion based on patient's perception of recovery.(15) Therefore, the purpose of this study is to 1) explicate the changes in patient perceived overall recovery after stroke during outpatient rehabilitation at a rehabilitation center; 2) identify factors related to patient perceived overall recovery after stroke; and 3) identify patients showing corresponding results on patient perceived overall recovery and walking ability, balance, depression and anxiety, peripheral muscle strength and fatigue. Based on literature search, we hypothesized that performance based measures for walking ability and balance were most likely to be related to the patient perceived overall recovery.(9,10)

METHODS

Subjects

An existing dataset of the FITstroke study was used for this secondary analysis. The FITstroke study is a multicenter single blinded, stratified randomised controlled trial. It was originally designed to evaluate the effects and cost-effectiveness of a structured, progressive task orientated circuit class training program, compared to usual physiotherapeutic care during outpatient rehabilitation in stroke patients. The intervention took place after the patients got discharged from inpatient rehabilitation at different rehabilitation centers. Data collection lasted to 24 weeks after randomization, a total of 250 stroke patients were included.(18,19) Further details of the FITstroke study were described elsewhere.(18,19)

Measures

The following outcome measures were included in this study and are hypothesized to be potentially related to the patient perceived overall recovery. The outcome measures are selected to represent each domain of the International Classification of Functioning (ICF) model. When several outcome measures could represent the same ICF-domain, the most frequently used outcome measure used in stroke rehabilitation was selected based on clinical expertise and frequency counts found in literature.(20) The Stroke Impact Scale was evaluated at the start of outpatient rehabilitation, 6 weeks, end of FITstroke intervention at 12 weeks, and follow-up at 18 and 24 weeks. The other outcome measures were evaluated at start of rehabilitation, end of FITstroke intervention at 12 weeks and follow-up at 24 weeks.

Stroke Impact Scale (SIS)

The SIS version 2.0 is a self-reported, stroke specific measure that includes 59 items in 8 domains related to activities and participation.(21) Only one domain of the SIS regarding patient perceived recovery after stroke was used in this study.

The patient perceived overall recovery is rated on a visual analogue scale from 0 (no recovery at all) to 100 (fully recovered). The SIS has shown excellent clinometric properties in terms of construct and concurrent validity, test-retest reliability and responsiveness.(22,23) Each of the domain scales of the SIS showed a good criterion validity and the SIS was also found to be useful for evaluating effectiveness of interventions of stroke rehabilitation in community setting.(24)

Six minute walk test (6-MWT)

The 6-MWT is a measure that assesses the distance that a patient is able to walk in a self-selected walking speed in a period of 6 minutes. The 6-MWT is frequently used in rehabilitation of chronic stroke patients and provides insight into the patient's walking speed, gait and endurance level. It has an excellent test/retest reliability.(20,25)

Timed get Up and Go test (TUG)

The TUG is frequently used to identify the patient's balance and risk of falling.(20,26) To complete the test, the patient must be able to stand up from the chair, walk 3 meters and turn back. The time it took to complete the test is measured and a cut-off point can be used

to indicate a higher risk of falling. In stroke patients the cut-off point is estimated at a total score of >14 seconds to perform the test.(27)

Motricity Index (MI)

The MI consists of 6 items and assesses the strength in upper and lower paretic limb. Scores per item range from 0-33 and a total score of upper and lower limb can be calculated. This measure can be used to evaluate the muscle strength during rehabilitation and is proved to be reliable and valid.(28) The MI was found to be highly reliable in the chronic stroke population when assessment is done by one rather. (29)

Hospital Anxiety and Depression Scale (HADS)

The HADS consists of 14 items and measures mood, emotional distress, anxiety, depression and emotional disorder. The measure is widely used and the total score may be regarded as a global measure of psychological distress, higher scores indicate greater levels of anxiety or depression.(30) The HADS is proved to be valid, reliable and responsive to change.(31,32)

Fatigue Severity Scale (FSS)

The FSS is used to measure the impact of fatigue. It is a 9-item questionnaire with questions related to the severity of fatigue and the way fatigue interferes with certain activities. The maximum score is 63, the higher the score, the greater the level of fatigue. The FSS showed an intraclass correlation coefficient of 0.82.(33)

Analysis

Data were analyzed using SPSS Statistics version 21.(34) To be able to analyze all patients as one group in further analysis, patient demographics and primary outcome measure were compared between intervention and control group using independent sample t-test. Normality of the data was assessed by visual inspection of the normality plots.

To describe the changes in patient perceived overall recovery during and after outpatient rehabilitation, change scores between baseline, end of intervention period (at 12 weeks) and follow-up at 24 weeks were calculated. A change score >10% was considered as improved, change score = 0 as no change and change score <10 % as decline.

A univariate regression analysis was used to determine the relation between the patient perceived overall recovery and performance based outcome measures. A correlation between 0.10 and 0.29 was considered small, 0.30 to 0.49 medium and 0.50 to 1.0 large.(35)

A backward stepwise conditional procedure was used for multivariate linear regression analysis using patient perceived overall recovery as dependent variable. A p-value of 0.2 in the univariate analysis was required for inclusion of a variable in the multivariate analysis. Multicollinearity statistics were calculated for the independent variables included in the regression analysis, a VIF value of < 0.10 was indicated as the occurrence of multicollinearity.(35) When multicollinearity occurred, one of the factors would be manually

removed. Factors in the multivariate linear regression model were found to be significant using a p-value of ≤ 0.05 .

For the factors included in the final regression model, change scores were calculated by subtracting the baseline scores from the follow-up scores at 24 weeks. Data was dichotomized using cut-off scores found in literature. Change scores larger than the measure's MCID were categorized as changed, changes smaller than the measure's MCID were categorized as unchanged. For the 6MWT a cut off value of $\geq 50,0$ meters change between baseline and 24 weeks was used. (36) The clinically important change of the SISv9 was determined as a difference of 10% (change of 10 points on the scale from 0-100).(37) Two-way contingency table was conducted to identify patients that reported corresponding results on perceived overall recovery and the objective outcome measures. To test if there was a significant association ($p < 0.05$) between the outcomes on objective and subjective measures, Pearson's chi-squared test was performed.

RESULTS

Participants

A total of 240 patients were included in data analysis. Using a T-test, no statistical significant differences were found in patient perceived recovery between the intervention and the control group of the FITstroke study. Therefore all 240 patients could be included as one group into further analysis.

Descriptive data

Mean age in the sample was 56.9 year, 81.1% of the patients suffered a cerebral infarction while only 18.8% suffered a cerebral hemorrhage. More male (64.8%) than female (35.2%) were included and the mean time since stroke was 96 days (SD=46.3). The characteristics of the included patients are presented in table 1.

Outcome data

Describing patient perceived overall recovery after stroke

One hundred and seventy patients experienced an increased or stable overall recovery during outpatient rehabilitation. This included 19.9% of patients reporting "no change" in overall perceived recovery and 23.7% of patients who experienced no change or a decline between the start of outpatient rehabilitation and measure at 12 weeks but reported an improvement between the measure at 12 weeks and the 24 weeks follow up.

Twenty-nine percent of the patients experienced a decline in overall recovery between start of rehabilitation and follow up, including 47 patients reporting increase between start of the outpatient rehabilitation and measure at 12 weeks, but a decline between the measure at 12

weeks and follow-up at 24 weeks. See figure 1 for complete flowchart of transitions in patient perceived recovery during outpatient rehabilitation.

Univariate regression analysis

Significant but small correlations were found between the patient perceived overall recovery and walking ability (6MWT; $r = 0.308$, $p < 0.000$), peripheral muscle strength (MI; $r = 0.227$, $p < 0.000$), depression and anxiety (HADS; $r = 0.281$, $p < 0.000$) and fatigue (FSS; $r = 0.188$, $p = 0.003$). Correlation between patient perceived overall recovery and balance was not significant (TUG; $r = 0.113$, $p = 0.080$) and therefore not included in the regression model. (Table 2)

Multivariate regression analysis

The regression model that included all factors with a significant correlation ($p < 0.05$) with the patient perceived overall recovery explained 16.5% of the total variance. Significant predictors of patient perceived overall recovery were found to be walking ability ($p = 0.000$), peripheral muscle strength ($p = 0.018$), depression and anxiety ($p = 0.003$) and fatigue ($p = 0.044$). Tests on multicollinearity indicated that these variables were not collinear and contributed uniquely to the SIS patient perceived recovery. See table 3 for the final regression model.

Matches between subjective and objective improvements

Table 4 shows the two-way contingency table used for identifying the patients showing improvement on both subjective and objective measures using the MCID of both measures as cut-off value for meaningful change. One hundred and fifty four patients (64%) showed corresponding outcomes on the SISv9 and the 6MWT. The chi-square test for independence indicated that there is a significant association between the SISv9 and the 6MWT (continuity correction 14.164; $p = 0.000$)

For the other factors included in the final model, no MCID or SDC for the stroke population could be found in literature, therefore this data could not be dichotomized and further analysis using contingency tables could not be done.

DISCUSSION

The present study did produce some interesting findings for practitioners working with patients in chronic phase following stroke. First, the progress in patient perceived recovery was described. We found that 60.6% of the patients experienced an improved perceived recovery during outpatient rehabilitation between baseline measure and 24 weeks follow-up. Secondly, factors related to the patient perceived overall recovery were identified using a multivariate regression model. We found that walking ability, anxiety and depression, peripheral muscle strength and fatigue were significantly related to the patient perceived overall recovery. The strongest correlation with patient perceived overall recovery was found in walking ability. The last aim of the study was to identify the patients showing corresponding results on both objective and subjective measures using a two-way contingency table. A significant association between patient perceived overall recovery and walking ability was found.

Several other studies were conducted which assessed the patient perceived overall recovery in stroke patients. One of these studies was conducted by Tang et al. and investigated the relationship between perceived recovery and the objective changes in walking after stroke. They found that patients with a high baseline score on the 6MWT were more likely to score higher on the perceived measure even though they went through the same absolute improvement as the patients who scored lower on baseline. Corresponding to the results of this study, Tang et al. also found that changes on the 6MWT were correlated to the perceived change.(38)

Recently, van Delden et al. investigated the characteristics of patients showing a match or a mismatch between objective and subjective improvements in upper limb functioning after stroke. They investigated one objective measure for hand function in comparison to two subjective measures where the patients could score their change regarding hand function. They found a percentage of 69% and 66% of "matchers" on both tests, which is in the range of our findings of 64% matching between the 6MWT and SISv9.(39)

It was hypothesized that both walking ability and balance would be related to the patient perceived overall recovery. In the present study the strongest correlation was found between walking ability and patient perceived overall recovery, while balance was not found to be significantly correlated. Therefore, the previously stated hypothesis could neither be accepted or rejected. The most frequently reported therapy goal during rehabilitation is the improvement in walking ability and balance (9,10) but the results of the present study did not show a significant correlation between patient perceived overall recovery and balance. In the FITstroke study, balance was measured with the TUG which assesses the dynamic balance. Using another measurement, for example a measure assessing both dynamic and static or only static balance could provide other results and may demonstrate the hypothesized relation between balance and patient perceived overall recovery.

A strength of this study is that the factors that were included in analysis were chosen according to the ICF-model, representing all different domains of the model. The results showed that changes in all different domains could influence the change in patient perceived overall recovery.

Another strength of this study is that the number of patients included for analysis is large and demographics show that the sample does represent the general population according to the proportions men/woman and cerebral hemorrhage/cerebral infarction. This means that the results of this study could be generalized to the total population of stroke patients in the Netherlands.

Some limitations should be noted when interpreting the results of this study. First, patients included in the study were discharged from the rehabilitation center when they were included in the study. Mean time between stroke and discharge from rehabilitation center was found to be 96 days. Results of patient perceived recovery could be different for patients in other phases of recovery with a different lapse. Other limitations might be that the SISv9 asks the patient to rate their overall recovery after stroke onset, which could lead to recall bias. Besides, the definition of overall recovery was not mentioned in the questionnaire which leaves room for each patient to interpret the question differently. This could lead to variety in answers based on the difference in interpretation instead of the variation in perceived recovery.

The final regression model could not explain all of the variance in the change scores of the SISv9. This indicates that there might be other factors related to the patient perceived recovery after stroke that have not been identified yet.

Further investigation on this subject is needed to obtain more knowledge of the different factors related to patient perceived overall recovery. When the factors related to patient perceived overall recovery are clear, they could be addressed during the multidisciplinary rehabilitation. Addressing these factors may lead to a higher score on patient perceived overall recovery and therefore eventually a higher degree of social participation after stroke. (14) The related factors could also be used for setting and evaluating therapy goals during rehabilitation.

In further research, it would also be interesting to investigate if factors are differently related to the patient perceived overall recovery when the patients are divided into two subgroups, one group scoring high on perceived recovery and the other group scoring low at perceived recovery at baseline.

For many objective measures, no Smallest Detectable Change (SDC) or Minimal detectable change (MCID) could be found in literature for this population. But the instruments are used daily by physicians to assess the progress of rehabilitation. More research on this subject is needed to know whether the changes that they measure during rehabilitation are relevant. Patient perceived overall recovery could even be used to determine a MCID of an objective measure, to know more about the relevance of changes from the patients perspective.

CONCLUSION

In conclusion, the majority of the patients did experienced an increase in their overall recovery after stroke during the outpatient rehabilitation. The patient perceived overall recovery was found to be related to walking ability, peripheral muscle strength, depression and anxiety and fatigue. These factors could be addressed during rehabilitation and could be used for setting and evaluating therapy goals in order to facilitate a more patient-centered approach in stroke rehabilitation.

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APPENDIX

| Table 1 Patient characteristics (N=240) | |
|--|-------------------|
| | Mean(SD) or N (%) |
| Age | |
| | 56,9 (10,3) |
| Time since CVA (days) | |
| | 96 (46,3) |
| Gender | |
| Female | 88 (35,2) |
| Male | 162 (64,8) |
| Treatment group | |
| Intervention | 126 (50,4) |
| Controle | 124 (49,6) |
| Type CVA | |
| Cerebral hemorrhage | 47 (18,8) |
| Cerebral infarction | 203 (81,2) |
| Type infarct | |
| TACI | 7 (2,8) |
| PACI | 96 (38,4) |
| LACI | 73 (29,9) |
| POCI | 27 (10,8) |
| Lateralisation CVA | |
| Left | 92 (36,8) |
| Right | 118 (47,2) |
| Brainstem | 20 (8) |
| Cerebellum | 20 (8) |
| Hemiplegia | |
| Left | 129 (51,6) |
| Right | 110 (44) |
| Bilateral left side most affected | 9 (3,6) |
| Bilateral right side most affected | 2 (0,8) |

CVA= cerebrovascular accident; TACI= total anterior circulation infarct; PACI= partial anterior circulation infarct; LACI= lacunar infarct; POCI= posterior circulation infarct

Table 2 Correlation from univariate regression analysis performed with the change score of SISv9 as dependent variable

| | r | p |
|------|----------|----------|
| 6MWT | 0.308 | < 0.000 |
| MI | 0.227 | < 0.000 |
| HADS | 0.281 | < 0.000 |
| FSS | 0.188 | 0.003 |
| TUG | 0.113 | 0.080 |

SISv9 = Stroke Impact Scale question 9; 6MWT= 6-minute walking test; MI= Motricity index; HADS= Hospital anxiety and depression scale; FSS= Fatigue severity scale; TUG= Timed up and go

Table 3 Linear regression model

| Model | R | R2 | Adjusted R2 | SEE |
|--------------|----------|-----------|--------------------|------------|
| | 0.423 | 0.179 | 0.165 | 15.317 |

| Table 4 Two-way contingency table for 6MWT and SISv9 | | 6MWT | | Total |
|---|---|--|--|--------------|
| | | No improvement (change score < 50) | Improvement (change score ≥ 50) | |
| SISv9 | No improvement (change score < 10%) | 52 | 46 | 98 |
| | Improvement (change score ≥ 10%) | 40 | 102 | 142 |
| Total | | 92 | 148 | 240 |

6MWT= 6-minute walking test; SISv9= Stroke impact scale question 9, patient perceived overall recovery

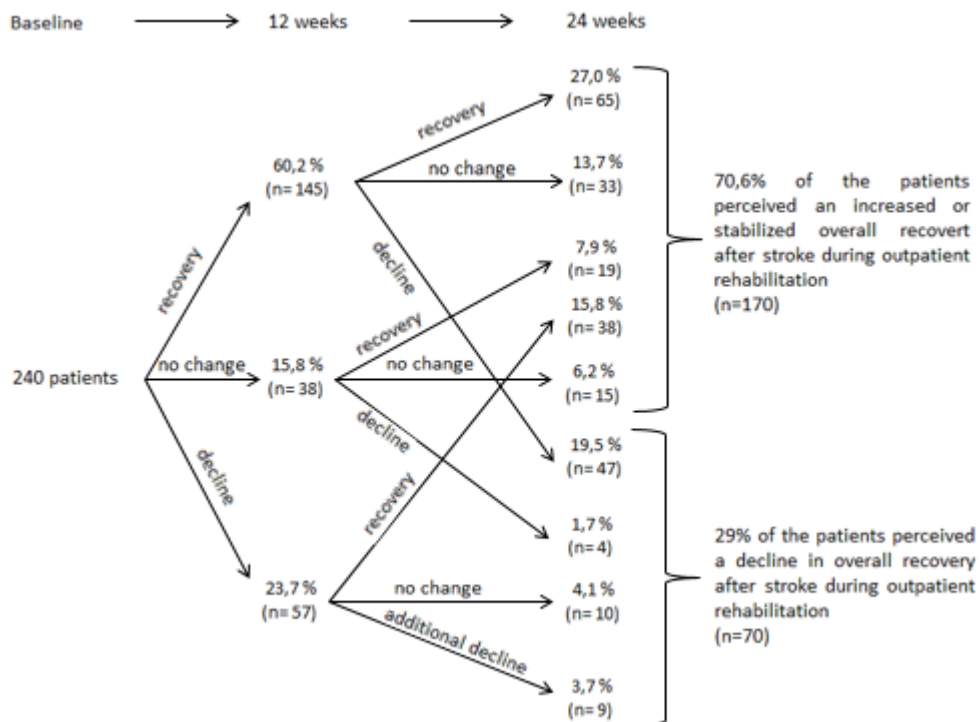


Figure 1 Transitions of patients in perceived overall recovery between baseline (start of outpatient rehabilitation), end of intervention at 12 weeks (T3) and follow-up at 24 weeks (T5). The left side of this figure illustrates the course of overall perceived recovery of the patients between these three time points. Decline refers to a decrease in patient perceived recovery, defined as a change score of <10%. The recovery refers to an increase in patient perceived recovery, defined as a change score of >10%. The right side of the figure illustrates the end results of the transitions in patient perceived recovery between start of outpatient rehabilitation and follow-up at 24 weeks.