

Pretesting the PDQ-39 IS, a health-related quality of life questionnaire for people with Parkinson's disease. Pilot study.

Hafdís Gunnbjörnsdóttir, RN and Ólöf Bjarnadóttir, MD,
Reykjalundur Rehabilitation Centre, Mosfellsbaer, Iceland



Introduction:

Parkinson's disease (PD) is a neurodegenerative disease where the most prominent symptoms are related to impairment in mobility and speech difficulty. Various non-motor symptoms may occur, like constipation, urine urgency or sleep, mood or cognitive disturbances that affect daily living. Health related quality of life instruments have been used to estimate various effects of multiple symptoms, and to evaluate them in terms of health. The patient's estimate of his status is very important to assess. Professionals can use that estimate as a guide regarding the patient's care, the program and to establish a comprehensive overview of how people with certain illnesses evaluate their condition. When translating a questionnaire it is important to know if people have uniform understanding of questions and that it is consistent. Statistical analysis is also a crucial part of validating questionnaires.

Objective:

The aim of this study was to pretest the Icelandic translation of the PDQ-39 (PDQ-39 IS). The scale was tested for reliability.

The PDQ-39 (Parkinson's disease Questionnaire) is a thirty nine item questionnaire which measures self-perception of health status and quality of life of individuals with PD. There are eight dimensions; mobility, ADL, emotional well being, stigma, social support, cognition, communication and bodily discomfort. The results are reported on a scale of 0 -100, where 0 indicates the most favorable health state.

Material/ Methods:

Patients with PD in the neuro-rehabilitation division of Reykjalundur answered the PDQ-39 IS during the first week of treatment. To assess the internal consistency of the scale, Cronbach's alpha was calculated for all eight dimensions, the limits were set at 0,7 and Item-total correlation limits set at 0,4. A neurological examination was recorded according to Hoehn and Yahr (HY), were I is little motor impairment and the highest number is V where the patient is almost bedridden.

Results:

23 men and 28 women with PD, filled out the questionnaire. Average duration of the disease was 5,4 years and the mean age was 67,8 years. Most patients were grouped in HY I-III. Cronbach's alpha >0,7 was in 5/8 of the dimensions (table I). Item-total correlation did not reach legality in nine questions out of 39. Seven of those questions were in the dimensions cognition and communication (table II).

Table I. Cronbach's alpha >0.7

	Iceland	Jenkinson-UK n=359
Mobility	0,93	0,94
ADL	0,81	0,89
Emotional well being	0,85	0,83
Stigma	0,72	0,80
Social support	0,80	0,69
Cognitions	0,42	0,70
Communication	0,41	0,79
Bodily discomfort	0,65	0,75

Table II. Item-total correlation > 0,4.

	Iceland
Mobility	All items > 0,4
ADL	All items > 0,4
Emotional well being	All items > 0,4
Stigma	1/4 item < 0,4
Social support	All items > 0,4
Cognitions	4/4 items < 0,4
Communication	3/3 items < 0,4
Bodily discomfort	1/3 item < 0,4

Conclusion:

The PDQ-39 IS is valid in five dimensions out of eight. It is invalid in three of the dimensions as the criteria in the Jenkinson's UK study was set at 0,7. Seven/nine questions are in the dimension of cognition and communication and have to be re-evaluated. The reason for this could be the lack of patients in more advanced stages of PD who would be more likely to have these symptoms. Another explanation could be that the sample is too small. The translation might have some flaws and in this case it is necessary to take another look at the translation and repeat the survey with patients in more diverse stages of PD and have a bigger sample. Such a study is on the drawing board. This study received a grant from Oddsjóður for statistic analysis.

References:

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Subjective evaluation of goals, formal meetings, health and communal service cooperation.

Hafdis Gunnbjörnsdóttir, R.N. Ólöf Bjarnadóttir, M.D. and Þorbjörg Oddgeirsdóttir, nurse assistant.
Reykjalundur Rehabilitation Centre, Mosfellsbaer, Iceland

Introduction:

In the neuro- and habilitation section at Reykjalundur Rehabilitation Centre patients with various neurological diseases, such as MS, Parkinson's disease, epilepsy, stroke, CP and brain injury are treated. Inpatient as well as outpatient programs are offered, depending on several factors like residence or severity of the impairments. Goal setting, involving the patient, is important in rehabilitation, but can be complicated because of coordination of work with social support networks, school-staff, employers and co-workers as well as education of family members. Evaluation of goals is important for the patient and team-workers, as well as quality registration for the institution.

Objective:

The aim of this study was to:

1. Evaluate rehabilitations goals.
2. Analyze the number of patients who needed structured services after discharge.
3. Analyze the need for family meetings, support, education and a future rehabilitation schedule. The patients answered two questions about their health.

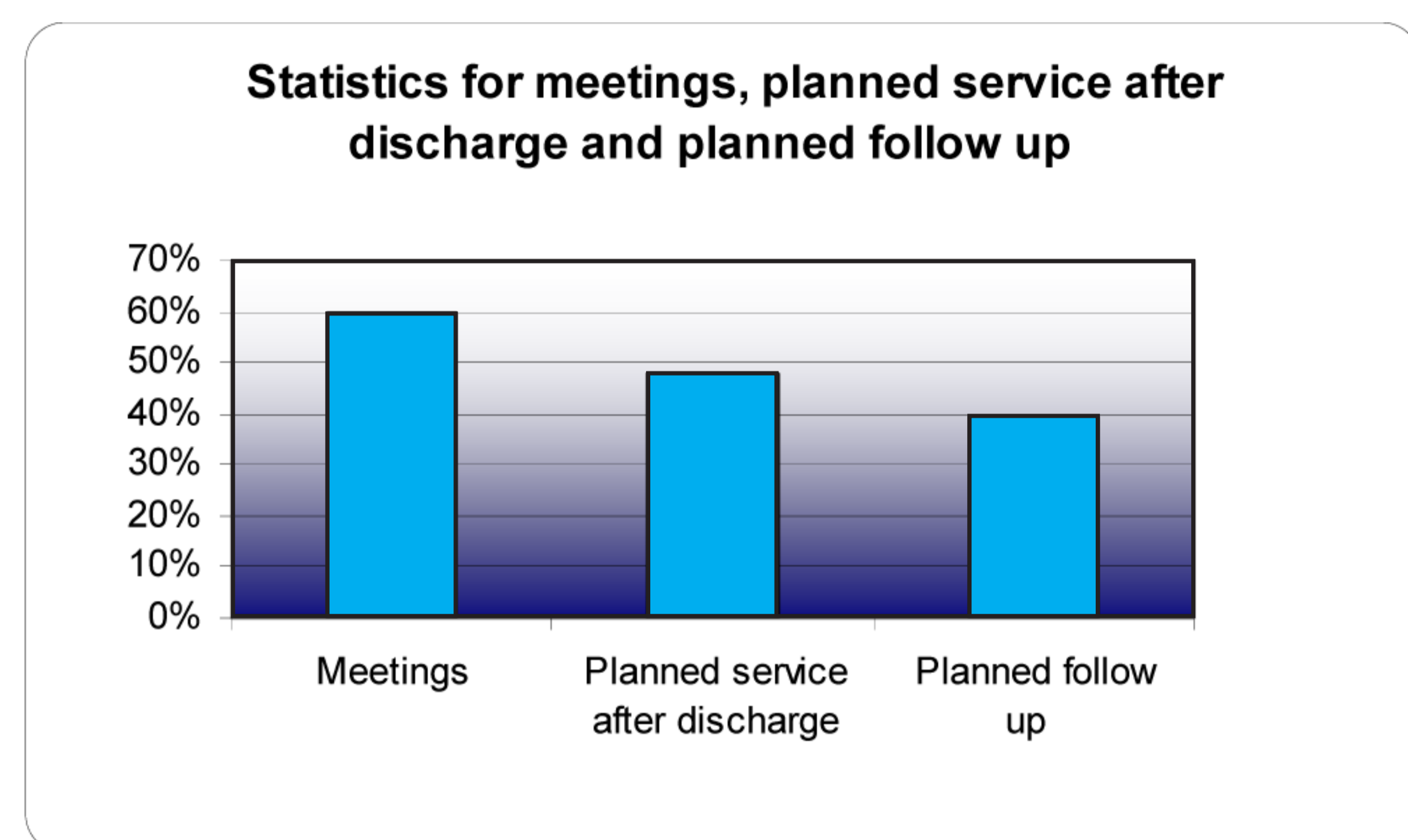
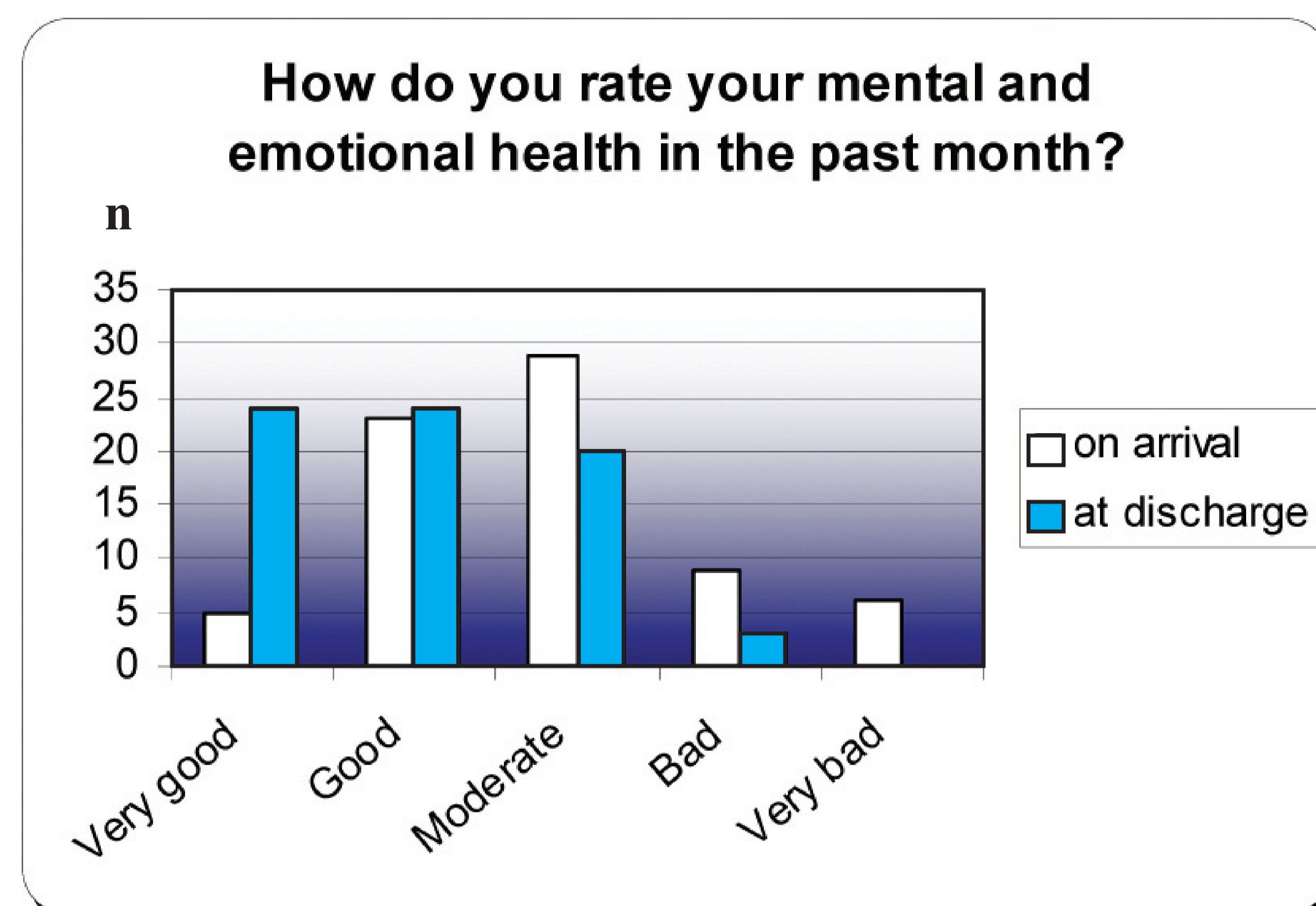
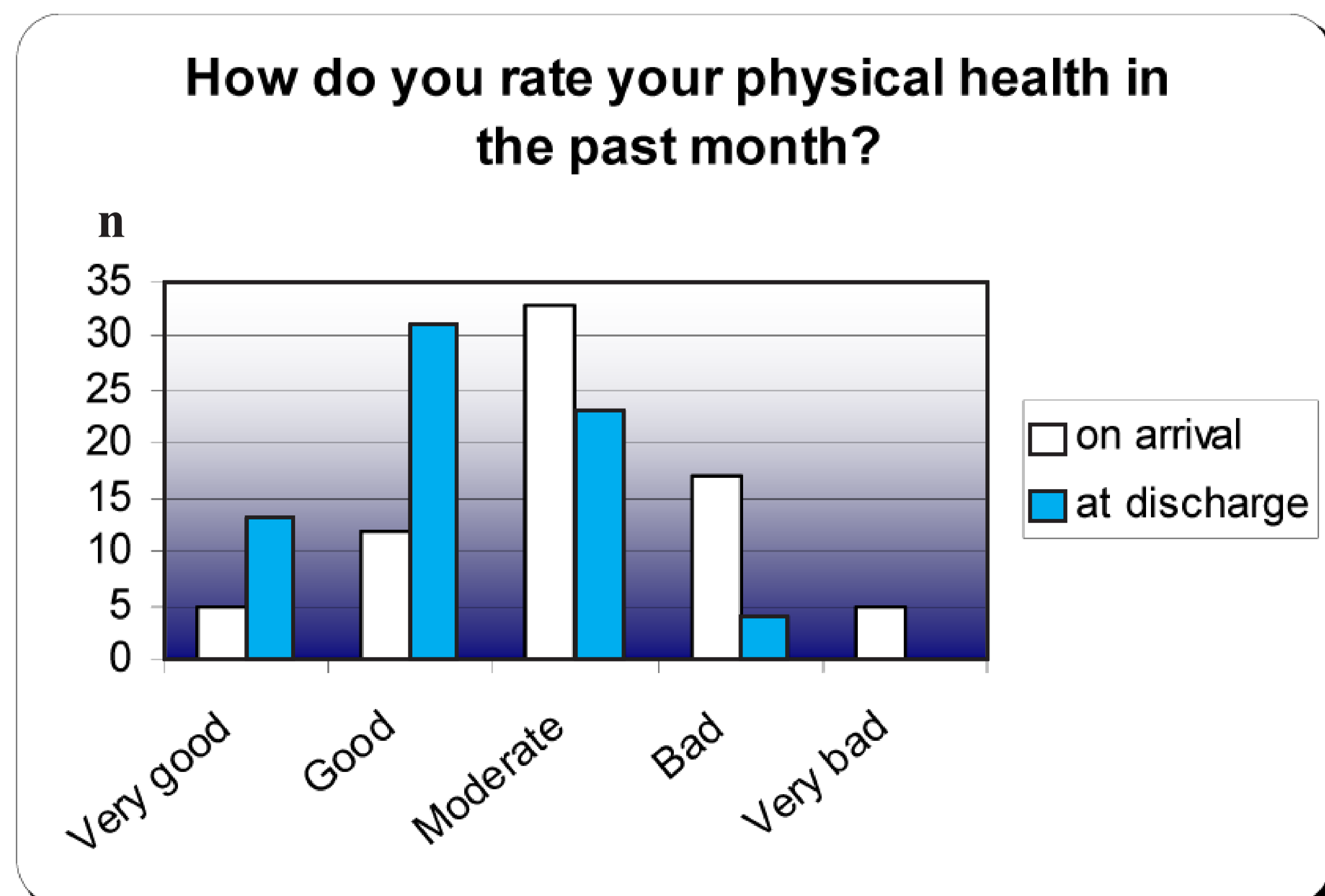
Material and Method:

In January to September 2006, health information for each patient was gathered and the number of meetings that patient/family member participated in was registered. Goals were set by the team in partnership with the patient and subjectively estimated at discharge. Patients were asked to answer two questions regarding their state of health and mental well being (scale 1-5).

Results:

94 patients came to the centre, results are shown for 74. Information on 20 patients was not gathered, including eight people with Parkinson's disease. Mean age was 52 years and 64% were male.

The goal were reached perfectly in 86%, partially in 11%, and not obtained in 3% of the cases.



Discussion:

Goals were reached in 86% of the cases. We feel that the approach to establish goals in cooperation with the patient seemed to encourage him or her in participating in the program and working towards the goals. All goals were interdisciplinary set and aimed at increasing activity and participation, and also to improve health and quality of life.

We believe that these goals attained are consistent with the patients' positive evaluation on the two questions about their health. An average of 2.8 meetings per week is high but we believe that this service is necessary because of the complex nature of interdisciplinary involvement. The team-members feel that more structured goal setting and cooperation with the social support networks and families heightens the likelihood of maintaining goals after discharge. This needs further studies.

References:

- International Classification of Functioning, Disability and Health, <http://www.who.int/classifications/icf/site/icftemplate.cfm>
- Wade, Goal Planning in Stroke Rehabilitation, Top Stroke Rehabil 1999