Leven na een beroerte
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Summary

In this study we describe how patients get on with regard to mortality, functional status and quality of life, during the first three years after they suffered a cerebrovascular accident (CVA).

In 1990 participating general practitioners (GP's) in Groningen, Friesland and Drenthe reported all patients with stroke, first ever or recurring. At set intervals over a period of three years these patients were visited by a researcher and each time their functional status was assessed using various measuring instruments. One year after stroke two-thirds of the surviving patients were extensively interviewed on the quality of life as they experienced it. The attending GP’s and nursing-home physicians supplied us with additional data on the current comorbidity every four months. The first six months of the follow-up have been reported elsewhere. This study concerns the long term, viz. the period of six months to three years after stroke.

The initial cohort consisted of 221 stroke patients, 131 female and 90 male, with a mean age of 77 years; at stroke onset 80% of them were living independently.

Chapter 1 comprises the introduction and Chapter 2 three case-histories.

In Chapter 3 mortality is discussed. Three years after stroke more than half of the initial cohort had died (a cumulative mortality of 54%). Patients who were still alive one month after stroke, continued to have a risk of dying twice that of elderly without stroke. During the first year this was mainly due to the severity of the stroke and concomitant cardiac morbidity. From then on the risk of death was mainly determined by age. In the period of one to thirty-six months after stroke, the subsequent consequences of the index stroke and cardiovascular pathology were causes of death in 70% of the deceased.

This high mortality due to cardiovascular diseases emphasizes the definite need for prevention, primary as well as secondary prevention.

Chapter 4 gives a report on the nursing-home care. One third of the one-month survivors had to face nursing-home care in any way and one fifth was admitted permanently in a nursing home during the three years period. Elderly people, females, patients with disturbed consciousness immediately following stroke, and patients known with dementia prior to the stroke, were more likely to be admitted to a
nursing-home permanently. Stroke might lead to nursing-home admission even after considerable time. Half of the permanent nursing-home residents had only been admitted until much later, sometimes not until the second or third year poststroke. The reason for these late admissions were usually stroke specific.
The large contribution of nursing-homes with regard to the care of stroke patients, contrasts strongly with the available relevant information. Because in future probably more patients will be hospitalized due to stroke for a short period of time, the importance of nursing-homes, in particular in regard to reactivate stroke patients, will certainly increase. Better understanding of indications for hospitalization and successful treatment strategies - what will increase the chances of living independently? -, is urgently needed.

Chapter 5 discusses co-morbidity and its consequences for the individual patient. Stroke related disorders such as hypertension, heart diseases and diabetes were found in resp. 56, 49 and 19% of stroke patients; this is about twice as high as compared to elderly of similar age and sex, not having suffered a stroke. Non-stroke related disorders occurred just as often as in elderly who had not suffered a stroke. Among these are a.o. diseases of the locomotor system, with a frequency of 41%; these disorders are particularly known for deteriorating the functional status of the elderly.

In the long term as well, stroke itself remained the most aggravating disorder for the patients interviewed. Then followed problems in regard to mobility, hearing and seeing; disorders which deteriorate the functional status and which lead to social impediments (dependence, isolation, leisure activities).

For stroke patients extensive comorbidity means deterioration of their functional status and quality of life and for GP’s it means more intensive and/or longer ‘monitoring’ of these patients. Besides, comorbidity has an important effect on research results, so ignoring it, would give distortion of reality and as such would produce incorrect information.

Chapter 6 covers the frequency of depressive disorders after stroke and the recognition thereof by the GP’s. The prevalence of depressions in a population depends considerably on the definition and the measuring methods which are applied. Using a self-rating scale (the Zung Depression Scale) we established a depression in 12% of our cohort, one year after stroke. This corresponds with other stroke research, in which self-rating scales were used. Furthermore it appeared that depression only slightly correlates with ADL-dependance.

All patients with a positive Zung-score were recognized by the attending physicians as being depressed, while some patients with a negative Zungscore were also
considered to be depressed by the physicians. In due course the Zung-scores varied more than the opinion 'depression' of the GP's. So GP's did not overlook depression. It does seem though, that in diagnosing depression they do not only consider behavioural and emotional factors of importance, but also the characteristics of the patients.

Chapter 7 and 8 are about the quality of life of patients who survived a stroke. The term 'quality of life' we allot for subjectively experienced quality of life.

Chapter 7 contains the account of an open interview about 'quality of life' with patients still alive one year after stroke. If the concept 'quality of life' is being defined at all, it is usually done by researchers and not by those concerned. On being asked, stroke patients seemed to consider autonomy (self-management of matters essential to function independently in daily life) as the most important dimension of quality of life. In their 'overall' evaluation of quality of life expressed by way of a report mark, they considered 'autonomy' as the most important issue to them. In a control group of elderly without stroke this was of less importance. Following autonomy came for stroke patients: social contacts and activities, general health status and next of kin. Interviews showed a wide variety of coping-strategies.

Chapter 8 further investigates report marks as measuring instrument for quality of life as experienced. Report marks in Dutch schools go from 0 (worst) to 10 (best), while the borderline between unsatisfactory and satisfactory lies between 5 and 6. One year after stroke patients evaluated the quality of their life as 'barely satisfactory', on an average of 6,5. This evaluation inevitably originates from a select group, viz. from patients who survived stroke and moreover who were able to be interviewed, in other words patients in the best condition. Yet their evaluation is considerably lower than that of elderly without stroke, who gave an average of 8,4. The report mark given by stroke patients proved to correlate with their living situation and with their functional status, particularly with their emotional functioning. Patients in nursing and residential homes gave lower marks than those living independently. Patients inclined to depression (i.e. high score on the Zung-depression scale) gave also a much lower report mark. The relation between a report mark and ADL-independence and social functioning was much less prominent. This seems contradictory to statements of patients themselves, saying they set great store by autonomy and social contacts and activities. This
could be explained by the fact that aspects, usually considered of importance for the quality of life, are ‘overruled’ by the mood at that particular time.

In conclusion one can state that a report mark is an adequate means to assess how a patient experiences his life after stroke. In combination with retrospective marks it indicates the course of illness as experienced by the patients. At an (unexpected) low score it could indicate a depression. If one wants to attune attendance to the personal values of the individual patient, one must become acquainted with these personal values. Asking the patient to give a mark for the quality of life as experienced, offers an adequate opening for a discussion about this matter.

Chapter 9 is about the GP’s management of stroke patients during the chronic phase of their illness. This management has to be ‘custom-made’ and will be focussed on improving the quality of life and not just on adding years. In this area there is, in our opinion, a coordinating role for GP’s. In order to render proper care the GP has to set up a strategy, incorporating into it paying attention, systematic and at set intervals, to the functional status of the patient, to the consequences of the disabilities as experienced by this patient, as well as to the ‘setting’, of which the patient is part. In doing so there should not only be time for medical intervention, but also for ‘listening’ and ‘compassion’. Illustrated by four case-histories, pitfalls are described, which may occur when managing stroke-disabled.

Chapter 10 states the conclusions of this study, and gives recommendations in regard to patient-care, research and training.