Quality of hospital care and health outcomes after stroke
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GENERAL DISCUSSION
Subject of this thesis is the quality of hospital care and the long-term health outcomes of patients who suffered a stroke. The study included a cohort of 760 consecutive stroke patients admitted to 23 randomly selected hospitals in the Netherlands. Data were abstracted from the medical and the nursing records, and all surviving patients were interviewed after 6 months, 3 years and 5 years. The data collection took place between June 1991 and December 1996.

7.1 Quality of hospital care

We introduced an instrument to measure the quality of several important aspects of medical hospital care for stroke patients (Chapter 2). The criteria included in this 'criteria map' were in part evidence-based, whereas part was based on expert opinions. The criteria were presented as 'optimal care trajectories', depending on the patient's clinical profile. The criteria map proved to be a reliable tool for an explicit case-by-case review of the quality of care. The instrument can be used to identify all patients who may have received suboptimal care.

It is well known that the major advantage of measuring the quality of the process of care, is an easy interpretation of the findings. In case randomized trials demonstrate that an intervention is effective, measuring the process of care will reveal the extent to which clinical practice has taken these research findings into account. From this point of view, high quality of care is care that is consistent with the outcomes of clinical trials.¹

In every day clinical practice, however, there may be several reasons why care is not consistent with the research evidence. First of all, the results of clinical trials are not always applicable to daily clinical practice.² The condition of the patients after treatment is not only determined by the care they have received, but is also determined by disease and by personal characteristics (i.e. case-mix). Therefore, clinical trials often include homogeneous samples of patients. However, in everyday clinical practice the patients are often older, are more seriously ill, or suffer from more comorbid diseases than patients in clinical trials.³

A related reason for inconsistencies between clinical practice and research evidence is that the results of trials, which are based on groups of
patients, are difficult to interpret for individual patients. Even in case the evidence is convincing for a heterogeneous sample of patients, this does not necessarily mean that the benefit for each individual patient equals the overall trial results.\textsuperscript{2,4,6} Actually, some patients may be harmed even when the mean overall trial result is positive.

Another reason for not treating patients according to research evidence is that patients can favor another treatment.\textsuperscript{5} For example, they might prefer a higher risk on a poor outcome to lower the burden of treatment. For example, it has been demonstrated that 16% of all stroke patients with atrial fibrillation rated the utility of warfarin therapy so low that their quality-adjusted life expectancy would be greater with aspirin.\textsuperscript{7}

Many aspects of medical care evidence are incomplete or contradictory. In these cases, criteria for optimal care are usually derived from consensus meetings with experts. However, since even experts can be pooling ignorance as much as distilling wisdom, other clinicians may disagree with these consensus-based criteria.\textsuperscript{8}

We encountered both the problem of applying group results to individual patients and of a lack of evidence when designing the individual care trajectories in the 'criteria map', and in interpreting the results. It was impossible to define conclusive cutoff values, below or above which a diagnostic or therapeutic procedure was indicated. Furthermore, the participating neurologists argued that deviations from the optimal care trajectory happened because they expected little benefit for these particular patients because of high age, or severe illness. It was argued (Chapter 2), that there are two possible solutions to this problem. One is to apply the criteria only to the 'ideal' patients, this means the patients most likely to benefit from the treatment. However, in this approach quality is evaluated for a selected sub-sample of patients. The other approach, the one we preferred, is to include all 'potential' patients, i.e. those patients who \textit{might} benefit from treatment. This means that we identified all patients who may have received suboptimal care.

In the early stage of our study, new research evidence became available with regard to the performance of carotid endarterectomy.\textsuperscript{9,10} In our criteria map, performance of ultrasonography was prescribed in all patients with a carotid territory infarction. Only patients with either a very poor prognosis upon admission, or patients who died during the
admission, were excluded from this criterion. However, due to the new evidence, present guidelines indicate that carotid endarterectomy should only be performed in patients with non-disabling strokes.\textsuperscript{11} Interestingly, we could not demonstrate any systematic differences in the number of patients undergoing ultrasonography between hospitals that were included before, and hospitals that were included after publication of the new evidence.\textsuperscript{12}

Our study showed that a substantial number of stroke patients might have been deprived from diagnostic procedures or potentially beneficial treatments (other than the performance of ultrasonography): a diagnostic CT scan, reversal of anticoagulant treatment, treatment of hypertension, and antiplatelet treatment. Although possible suboptimal care concerned mostly the oldest and most seriously ill patients, we also demonstrated that a substantial part of the youngest and the least disabled patients received possible suboptimal care. Based on these results we conclude that care for stroke patients in the Netherlands can be improved.

Another aspect of our study on hospital care for stroke patients concerned the length of stay and discharge delays (Chapter 3). We demonstrated that, according to treating physicians, about 50\% of the mean length of hospital stay (28 days) was essential for diagnostic or therapeutic procedures. About 10\% of the mean length of hospital stay concerned essential medical or nursing procedures which could have been performed outside the hospital, provided that care for stroke patients is organized differently. The remaining days, about 40\% of the mean length of hospital stay, were superfluous from a medical point of view. Usually, these days were spent waiting for transfer to a nursing home. This practice prevented that patients received adequate rehabilitation care, which is usually insufficient in acute care settings in the Netherlands. The discharge delays were not only due to lack of long-term care facilities, but also due to inefficient hospital discharge procedures. These data suggested that the length of hospital stay can be reduced without compromising the quality of care.

Since the end our study, the mid-nineties, major changes have occurred in Dutch stroke care: implementation of stroke units and stroke services. A stroke unit might be defined as a ward or a team exclusively for the management of stroke (dedicated stroke unit).\textsuperscript{13} It may be best
characterized as coordinated multidisciplinary care by specialized medical and nursing personnel. A stroke service can be defined as a structural arrangement between various disciplines and institutions involved in the care for stroke patients. The participating institutions are collectively responsible for the transfers between the care facilities and for the quality of care as a whole. Usually, a stroke service includes a stroke unit. The most recent systematic review of randomized trials, which compared organized inpatient stroke care on a stroke unit with contemporary conventional care, showed a long-term reduction of deaths and combined poor outcomes: death or dependency, and death or institutionalization. Also, the length of stay in hospital or institution reduced considerably. Moreover, the results did not depend on patients' age, sex, or stroke severity.\textsuperscript{14} Since the specific organization of a stroke unit depends on local circumstances there is a considerable heterogeneity between different stroke units. As yet, however, no single factor or small group of factors has been identified as being responsible for the favorable effects.\textsuperscript{15} Recently, all evidence with concern to the cost-effectiveness of treatment and secondary prevention in stroke were reviewed. This review showed that establishing a stroke service and a multidisciplinary team that delivers organized care should have highest priority in stroke care.\textsuperscript{16}

Currently, stroke services and stroke units are set up in various regions of the Netherlands. This type of care organization, which stresses care protocols and explicit criteria for admission and transfers of patients, is recommended in the most recent Dutch guidelines for stroke.\textsuperscript{11} As we argued (Chapter 3), the introduction of this policy in the Netherlands will probably lead to a substantial reduction in hospital days, whereas the quality of care will improve.

### 7.2 Health outcomes

Since many patients die after a stroke, patient outcomes should always be expressed in terms of mortality. The assessment of outcomes should generally be complemented with data on functional health of the surviving patients. These functional health outcomes may be hierarchically described according to the ICIDH classification\textsuperscript{17} or the Quality of Life (QoL) concept. In the ICIDH classification, an impairment is defined as a loss or
abnormality of a structure or function at organ level and is therefore a
direct manifestation of the disease. A disability reflects the consequence of
the impairment on a personal level. A handicap is a disadvantage for a
given individual, resulting from an impairment or disability, that limits or
prevents the fulfillment of a role that is normal for that individual. The
World Health Organization is currently developing a new version of the
ICIDH classification, the ICIDH-2.18 In this new classification scheme,
health is viewed more positively and more attention is directed at
environmental factors as possible determinants of functioning. Another
concept frequently used to describe health outcomes is Quality of Life
(QoL). Although, no formal definition exists, there is a consensus that QoL
should encompass physical, psychological and social aspects of health.19,20
Moreover, QoL is usually considered as a personal and subjective
evaluation of a patient's health status.

In general, higher levels of functioning are the most meaningful to the
patients themselves. Nevertheless, a recent review on stroke outcome
measures in acute stroke care showed that death and impairments are still
the most commonly used outcome measures. Disability is measured in less
than 50% of the trials and handicap or QoL are very rarely assessed.21 One
of the reasons that QoL is seldomly assessed in stroke trials may be the
lack of a comprehensive, yet feasible instrument, reason why we developed
such an instrument (Chapter 4).

The Sickness Impact Profile (SIP) is a reliable and valid generic
instrument to assess quality of life.22-24 In stroke research, the SIP is
especially useful because it emphasizes observable behavior instead of
subjective health perceptions. This means that SIP data can be collected
through proxy respondents if patients are not able to communicate due to
language or cognitive problems.25 A major disadvantage of the SIP is its
length, in stroke populations it usually takes 30 minutes or more to
complete the 136 items. In view of the need of a comprehensive, shorter
QoL measure, we developed a short stroke adapted SIP. We described the
procedure used to reduce the original SIP (12 subscales and 136 items), to
8 subscales with 30 items for the new Stroke Adapted SIP-30 item version
(SA-SIP30). This large reduction of items proved to have a relatively small
loss of clinical information, which was most obvious in patients with a
seriously impeded health. Furthermore, the reliability and the validity of
the SA-SIP30 were comparable to those of the original SIP 136 item-
version.

Although originally presented as a measure of 'functional health',
many authors consider the SIP as a measure of 'health-related QoL'. For
example, QoL reviews usually include the SIP next to other QoL
instruments such as the Nottingham Health Profile or the SF36.26-28 At the
same time, although there is no formal definition, QoL is regarded
commonly as a subjective evaluation of the health status. The
incorporation of patients' values and preferences reportedly distinguishes
QoL from all other measures of health.29 It is obvious that the SIP, which
emphasizes observable behavior, does not meet this criterion. Therefore,
some authors employed the SIP as a measure of disability rather than as
one of QoL.30,31 In Chapter 5, we compared the (SA)SIP(30) to other
frequently used stroke outcome measures derived from both the ICIDH
model and the QoL model. We could demonstrate that the total scores of
the two SIP versions were substantially associated with both ICIDH
disability measures and with the physical QoL domains, but were not
associated with health perceptions or other psychological QoL domains.
Therefore, we concluded that the (SA)SIP(30) primarily measures
disability. Still, we recommend its use in stroke research because both SIP
versions are more comprehensive than generally used disability measures
such as the Barthel Index or the Rankin scale.

Despite the efforts to develop short and clinically meaningful
instruments for the most essential domains of functioning, their use is
hampered by lack of clarity about the clinical meaning of the continuous
scale scores. Based on various different external criteria we present
different cut-off scores for 'poor' outcomes to facilitate the use of the
continuous scale scores of the (SA)SIP(30) in clinical trials. However, this
does not completely solve the interpretation problems. For example, a total
score of 10 on the Barthel Index can be achieved by a patient who reports
no limitations in dressing, eating and grooming, but has severe limitations
in climbing stairs or mobility. However, the same total score of 10 can be
achieved by a patient who reports moderate limitations on all items. A new
and promising approach to overcome these difficulties in interpretation is
the so-called equiprecise measurement.32,33 This approach aims at
developing unidimensional linear scales which can precisely place patients
in a continuum underlying the dimension of interest. All items, which describe the full continuum of functioning of the dimension of interest, are anchored. Therefore, each patient has to answer different items, according to his level of functioning, while the score precisely describes the position on the underlying concept. This new approach is currently in the developmental phase.\textsuperscript{34}

### 7.3 Quality of hospital care and health outcomes

Instruments to assess health outcomes can be used in trials, to establish the effectiveness of care, but can also be applied directly when evaluating quality of care. Outcomes of the different providers can be compared and one may easily assume that the healthcare provider with the best outcomes performs care with the highest quality. However, there are several limitations to this outcome approach.

The major disadvantage of assessing quality of care by means of health outcomes is the insensitivity of outcome measures to detect differences in the quality of the process of care.\textsuperscript{1-35} This can be illustrated with our results which could confirm the overall poor prognosis after stroke (Chapter 6). Five years after the onset of stroke only 38% of the original Dutch cohort of 760 patients was alive. Moreover, only 50% of the surviving patients was able to have a completely independent life. The severity and type of stroke are very powerful determinants of both mortality and functional health. When we compare the impact of stroke type with that of, for example, the use of antiplatelets after stroke, then it is clear that the type of stroke far more determines the health outcomes. For example, our 5-years mortality for patients with a lacunar infarction was 39% while the mortality for patients with a (sub)cortical infarction was 65%. In contrast, the use of antiplatelets after an ischemic stroke reduces the 2-years risk of a new vascular event from 23% to 19%. The long-term effects (3rd and 4th year) of antiplatelet medication after stroke is even smaller or may be absent.\textsuperscript{36}

The strong association between clinical and personal characteristics on the one hand, and health outcomes on the other, also shows that an adjustment for case-mix differences is crucial when assessing quality of care by outcome measures.\textsuperscript{37} However, problems with adjustment for case-
mix differences are, firstly, to identify major prognostic factors, and secondly, to measure these factors in such a way that appropriate adjustments can be made. Yet, another issue in outcome assessment is the timing of the measurements. The longer the time interval between care and outcome assessment, the more likely it is that other factors will influence the outcome. However, some treatments, such as secondary prevention measures, are specifically meant to improve the health of a patient on the long-term.\(^{38}\) Finally, even if providers with a poor quality of care can be reliably identified, outcome measures alone are not sufficient to reveal which part of the process needs to be improved.\(^{39}\)

Although outcome measures do have their limitations, this does not mean that they cannot be useful for the assessment of quality of care. First of all, if there is no scientific evidence about the process of care, outcome measurement may be the only option. Secondly, outcome measurement may be the only option even when evidence is available. For example, although the effectiveness of stroke units has been established, it remains as yet unclear why stroke units work. Therefore, it is not clear which process should be measured in assessing quality.\(^{40}\) Thirdly, outcome measurement may be preferred on more theoretical grounds. The objective of medical care is to improve the patients' outcome: to prolong life and to enhance its quality. Therefore, improving the quality of the process should always be followed by a close description of the outcomes.\(^{41}\)

### 7.4 Future research

There is still a lot to be done in the field of assessment and improvement of quality of care and health outcomes after stroke. Whenever possible, process measures should be the first choice in assessing the quality of care. To overcome the major difficulty of process measures, that is to apply group results to individual patients, more knowledge about the variability of treatment effects is indispensable, in other words 'what works for whom?' Future clinical trials should therefore pay more attention to the variability of treatment effects. In addition, future clinical trials should include less homogeneous groups of patients. Those trials should primarily be aimed at the patients who are most often seen in daily clinical practice. Despite these recommendations, it is unrealistic to expect that all elements
of the process of care, especially the interaction between all these elements for all types of patients, will one day be scientifically demonstrated. Therefore, monitoring the outcomes of care will always be indispensable. Outcome assessments will be enhanced by developing feasible case-mix measures that reflect the total burden of disease. Furthermore, new linear hierarchical scales may facilitate interpretations of outcome measures. Both process and outcome measures should more clearly incorporate the preferences of the patients. An essential and new development in health care will be the routine collection of process and outcome data. These data ideally should be collected during the routine of patient care and should be processed in ways to ensure measurements of elements of quality of care. Healthcare workers can then be provided with critical information on process and outcome.

The next question is how to improve the quality of care and how to prevent suboptimal care. Since physicians have to deal with a large number of guidelines for different conditions and since new research evidence is published regularly, keeping up with evidence has become practically impossible. All this information can be somewhat trimmed if research findings are prioritized. An intervention should only be adopted if the benefit is patient relevant and sufficiently large relative to risks as well as to costs.\textsuperscript{42} This prioritizing can be justified from a societal perspective: patients should be treated optimally instead of maximally.\textsuperscript{43} However, efforts are also needed to provide a wider range of high-quality information to be used in clinical settings.\textsuperscript{44} A new approach for this is the so-called Computer-based Decision Support Systems (CDSS). CDSS may be defined as any software designed to directly aid in clinical decision making in which characteristics of individual patients are matched to a computerized knowledge base for the purpose of generating patient-specific assessments or recommendations that are then presented to clinicians for consideration.\textsuperscript{45} A recent review showed a beneficial effect of CDSS on clinician behavior in 66% of the 65 reviewed trials.\textsuperscript{45} Making evidence quickly available to clinicians increases the extent to which evidence is sought and incorporated into patient care decisions.\textsuperscript{46} Although CDSS enhances the clinical performance, its effects on patient outcomes are scarce.\textsuperscript{45,47} Given the rapid evolution of CDSS such studies are essential.
So far, we have stressed the need for more applicable research evidence and better ways to disseminate the available knowledge. Although indispensable, this will not be sufficient to change daily medical practice. Human behavior is not only based on rational cost-benefit decisions but also depends on many other factors. Examples are: the motivation to change, the expected rewards associated with the change, and the attitudes and beliefs of authoritative others (colleagues or hospital managers). Currently, several methods are available to implement guidelines and to change clinical practice. These methods are based on various theories about behavioral change.48,49 So far, none has proven to be superior. Therefore, a step-wise approach with integration of different methods may be the best way to implement changes. The need for an explicit implementation strategy is also recognized in the new national Dutch guidelines for stroke care.11 A special task group will prioritize the recommendations and make an inventory of possible obstacles in carrying out these recommendations. Depending on the outcomes of this inventory, an implementation strategy will be formulated. Thereafter, the care for stroke patients will be regularly monitored and the results will be reported back. In this way, optimal care for the Dutch stroke patients will be supported.

7.5 References


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