

# Prioritisation of nursing care

## Material for discussion based on care undertaken for stroke patients

The report has been drawn up by a project group appointed by the Swedish Association of Health Professionals, the Swedish Society of Nursing and the Swedish Society of Medicine

# Contents

FOREWORD	3
SUMMARY	5
BACKGROUND	7
PURPOSE	9
METHODS	11
RESULTS – MODEL FOR PRIORITISATION WITHIN NURSING CARE	13
Literature search	13
Prioritisation of nursing problems in the case of stroke	13
Prioritisation of nursing care in the acute phase after a stroke	14
Prioritisation of nursing care during various phases	17
Prioritisation of support to relatives	19
PRIORITISATION WITHIN THE HEALTH CARE SYSTEM – OUTSIDE FACTORS	22
Legislation	22
Work on prioritisation at a national level in Sweden	24
Medical programme projects and prioritisation by county councils	26
The work of the Swedish Society of Medicine on prioritisation	26
Work on open prioritisation in other countries	27
SUMMARISING DISCUSSION	29
Open or closed prioritisation?	29
Is it possible to implement open prioritisation within nursing care?	30
Is it possible to make health economics assessments?	31
How are needs assessed?	31
FUTURE PERSPECTIVES	33
LITERATURE	34
APPENDICES:	
1 Nursing care in the acute phase after a stroke	36
2 Care planning	39
3 Comments concerning fundamental prioritisation principles	41
FOOTNOTES	44

Cover illustration: Marie Åhfeldt. Production: Swedish Society of Medicine. Print:

Tryckindustri Information, Stockholm 2004

# Foreword

To investigate whether it is at all possible to determine priorities within nursing care, the Swedish Society of Nursing and the Swedish Association of Health Professionals initiated a joint project with the Swedish Society of Medicine in the autumn of 2002. The intention was to benefit from the experience gained from the work of the Society of Medicine on issues concerning prioritisation.

In November 2002, a joint project group was formed with representatives from the three organisations. The purpose was to investigate whether it is possible to develop guidelines for open prioritisation of nursing care.

The members of the project group have been:

- Kjell Asplund, Director General of The Swedish National Board of Health and Welfare [Socialstyrelsen], co-opted Professor of Internal Medicine, member of the Prioritisation Committee of the Society of Medicine.
- Inga Berg, head of the enquiry, secretary of the Prioritisation Committee of the Society of Medicine
- Annika Berglund, nurse specialised in stroke treatment, Stockholm Söder Hospital [Södersjukhuset], appointed by the Association of Health Professionals
- Birgitta Engström, associate professor, university lecturer in Nursing, Umeå, Chairperson of the Swedish Society of Nursing
- Kerstin Hulter-Åsberg, associate professor, chief physician at the Medicine Clinic at the General Hospital in Enköping, Chairperson of the Medicine Committee of the county of Uppsala
- Catrine Jacobsson, University lecturer in nursing at Umeå University, field of research: nursing care in the case of stroke, and health economics
- Jan Stålhammar, District Medical Officer at Eriksberg Health Centre, working at the Department of Public Health and Nursing Studies, Uppsala University

Searches of the scientific literature show that there are some publications concerning nursing care and prioritisation. On the other hand, there are no scientific publications concerning nursing methods and prioritisation, either nationally or internationally.

Within eight important problem areas, various nursing tasks in stroke care have been graded into priorities, on a scale of 1 – 3. Specific subprojects have covered care planning and support to relatives. The most important conclusion of the project group is that it is possible to assign open, transparent priorities for nursing care in stroke.

The project group, not the organisations, is responsible for the content.

# Summary

- A pilot project on prioritisation within nursing care has been initiated by the Swedish Society of Nursing and the Swedish Association of Health Professionals in partnership with the Swedish Society of Medicine. The purpose was to investigate whether it is possible to develop guidelines for open prioritisation of nursing care. The project has been limited to nursing care in the case of stroke.
- Searches of the scientific literature show that there are some publications concerning nursing care and prioritisation. On the other hand, there are no scientific publications concerning nursing methods and prioritisation, nationally or internationally – this applies to nursing methods in stroke as well as for other diseases.
- It is the assessment of the project group that nursing care for stroke victims can be prioritised on the basis of the following fundamental criteria: need of nursing care, type of nursing care required, type of basic data for assessing the effectiveness of the care (scientific studies of varying quality, assessments based on clinical experience), resource consumption, health benefits of the care and the consequences of doing nothing.
- Within eight important problem areas, various nursing tasks in stroke care have been graded into priorities, on a scale of 1 – 3. Specific subprojects have covered the care planning and support to relatives.
- Important limitations on the project work and its results are the meagre availability of basic scientific data for assessing effects and costs, as well as uncertainty about how open prioritisation might affect everyday health care.
- This report also includes a description of the legal basis for prioritisation in the health care system and ongoing work on prioritisation nationally and internationally.
- The most important conclusion of the project group is that it is possible to assign open, transparent priorities for nursing care in stroke. This pioneering work ought to be followed up by work aimed at further developing general models on which to base guidelines for prioritisation within nursing care. A system of open prioritisation could reduce the risk of randomness and the unintentional reallocation of resources.

# Background

When resources (time, equipment, money etc.) are limited, something has to be sacrificed to allow the most urgent work actually to be carried out. The word 'prioritise' means 'to give precedence to' – something is selected, something else is rejected or postponed. Prioritisation has always been made in the health care system but has not always been reported openly. Open prioritisations means reporting on which priorities have been made and the reasons why they have been made, so that all interested parties (patients, the general public, decision-makers and health care professionals) are kept informed and have the opportunity to influence the way in which priorities are made.

Prioritisation within health care can be made at several different levels. At the highest level, resources during the last decade have been redistributed so that more resources are assigned to drugs and high-technology equipment and less to nursing care<sup>1</sup>. It is not clear if this has resulted from conscious, open and evident prioritisation.

As regards assigning priorities within everyday care, previous models for open prioritisation have almost exclusively dealt with purely medical care. In straightforward cases, diagnosis-intervention pairings have been defined and then given a ranking. Examples of pairings like these are: smoking – short structured advice; ear inflammation – antibiotic treatment; extra-uterine pregnancy – surgery; stunted growth – supply of growth hormone.

The guidelines of the Swedish Board of Health and Welfare for care of cardiac disease, asthma, stroke, cancer, etc. include proposals for prioritising different medical activities. The Swedish Society of Medicine has recently completed a project in which several sections of the Society of Medicine drew up detailed lists of priorities<sup>2</sup>.

Although work is currently being carried out in Sweden to develop detailed prioritisation of strictly medical activities, little attention has been paid to open prioritisation within nursing care. It is in everyone's interest that the content and implementation of the nursing care is of the best standard conceivable, both as regards results and the way in which we use our resources. To be able to assign priorities more openly, there is a need for well defined basic data that includes an assessment of need, effects including an assessment of the basic scientific data and cost effectiveness of different nursing tasks. Basic values are important when prioritisations are made.

One method of dealing with values in health care is to base the care on a thoroughly considered basic view which is formulated in a care philosophy. In different target documents, several of the Swedish county councils base their nursing care policy on humanistic values, placing great

emphasis on the equal value of all people and on solidarity with others<sup>3</sup>.

When the values of nursing care activities are discussed, it should therefore be relevant to start with what constitutes good care. This is largely a matter of relating and interacting. In studies in which patients have been interviewed, it emerged from a majority of the statements that good nursing care either fully or partially, concerned relationships.<sup>4</sup> The things considered important included feeling respected, being listened to, taken seriously, being believed, being comforted etc. Poor nursing care could largely be said to be when the patients felt ignored and insulted. Interaction was a central feature of the experience of good nursing care. Great importance is therefore attached to the carer's attitude as regards the value of the nursing care provided. When nursing measures are being chosen in a patient situation, interaction with the individual is thus of the highest importance.

The conditions for prioritising nursing care are partially different to those for medical activities. A number of questions arise: to what extent are nursing diagnoses applied analogously with medical diagnoses, and can nursing diagnoses be used as a basis for prioritisation? How should priorities be assigned when the basic scientific data for effects and resource consumption are inadequate? Is it at all possible to rank fundamental requirements such as assistance with personal hygiene, supply of fluid or need of comfort into a list of priorities?

Willman et al. have defined the terms 'nursing method' and 'nursing intervention'. The term 'method' is defined as a planned approach for achieving a predetermined result. The term 'nursing intervention' is clarified in the following: "In a broad sense, nursing interventions mean that staff become involved in collaboration with the patient, and where appropriate the patient's close relatives, formulate and define physical, mental, social and spiritual health goals. Nursing interventions span a wide area, from high-technology to moral support in existential crises."<sup>5</sup> This means that one method can contain several sub-components. The term 'method' can therefore be perceived both as "a package" of methods and also as sub-components of planned approaches which can be assessed. Since prioritisation takes place at group level, this report will use the terms 'nursing methods' and 'nursing activities' interchangeably with the same meaning. The term 'nursing intervention' will not be used in this work, since intervention implies an activity aimed at an individual person in a specific situation.<sup>6</sup>

# Purpose

To investigate whether it is at all possible to assign priorities within the nursing field, the Swedish Society of Nursing and the Swedish Association of Health Professionals initiated a joint project with the Swedish Society of Medicine. The intention of this was to benefit from the experience gained from the work of the Society of Medicine on prioritisation issues. In November 2002, a joint project group was formed with representatives from the three organisations. The purpose was to investigate whether it is possible to develop guidelines for open prioritisation of nursing care.

Early on in the discussions it was clear that the work would have to be limited to being a pilot project within a well-defined area. The choice fell on the medical diagnosis of stroke, because, among other things, there is some basic scientific data for assessing the value of nursing care in the case of stroke. The project group defined the following objectives:

- making an inventory of what has already been done as regards prioritising nursing care, particularly in the case of stroke
- identifying and structuring the most important nursing care for patients suffering a stroke, including care planning and support to relatives
- investigating the principal criteria on which the nursing care priorities can be based
- on the basis of the prioritisation principles, to provide examples of the way in which priorities within the selected nursing care area can be established
- presenting this material to groups involved in nursing care as a basis for more in-depth discussion on prioritisation

The intention was to cover general (e.g. the supply of nourishment and fluids) as well as specific (e.g. practising eating) nursing activities for stroke victims.

There are more details about assessments and basic principles for prioritisation in the bibliography to this document as well as in Appendix 3.

A narrative written by a patient in a research project illustrates the experience of suffering a stroke and the resulting eating difficulties.

As someone who has recently suffered a stroke, the only thing you can do is gratefully receive the expert care you get in a stroke unit. You cannot get out of bed, just look at the

ceiling. In my case, the paralysis from the stroke affected part of the windpipe and gullet areas. When that is the case, you have particular difficulty in letting liquid food and drink, pass down into your stomach. You cough easily. The menu during the first period consisted therefore mainly of thick gruels and soups. I had no appetite. That was quite unlike the usual me!! In the first six months I lost 15 kg in weight. That was the only positive thing I was able to record afterwards.

Not being able to drink and swallow, like healthy people do, is among the most serious of my problems. That is also intimately linked with speech itself. I can only remember that I was bothered with having unclear, slightly slurred speech that I gradually got used to and did not think about any more. Dysphagia or paralysis of the gullet – I don't know how my disability should be classified, but it is extremely unpleasant whatever it is called. Now I have learnt a technique of just letting the solid or liquid mouthful "slide" down the throat and that usually works.

But what was it like before? What do you do when you swallow? I just can't! Does anyone understand how it feels? Try it yourself with a little food! Let the mouthful you are chewing reach its goal, the stomach, without the normally subconscious impulse that makes it slide down through the gullet! I have to do that every time I swallow.

Coughing or hawking, which is normal now and then for clearing the throat, is another of the normal things in life that I no longer can or want to do. The actual interest in food, a quintessential part of all good appetites, has left me since the injury affected my brain. I go through agonies before every new meal.

# Methods

This pilot project has been limited to nursing care for stroke victims and to care planning and support to relatives.

By searching the major international databases (MedLine, CINAHL and EMBASE), using different combinations of the terms/search words 'nursing' and 'prioritisation' with the use also of closely related terms an inventory has been made of the current knowledge. Reference lists in the articles, which have touched on the subject in some way, have been examined to find further literature within the field. In addition, the members of the group have followed up all references that have been obtained in an informal way.

By a process of consensus, the nurses in the project group defined the central nursing care needs that there might be after a stroke and indicated important tasks for satisfying these needs. The overall ranking is described in more detail on page 13. As with the priority list from the Society of Medicine, in the first instance an attempt was made to prioritise needs and tasks on a scale of ten. However, this proved difficult to accomplish – the detailed subdivision was perceived as being poorly suited for nursing care and not all of the ten points were used. Because of this, a model was selected containing a scale of three points for each nursing task: 1 basic, 2 secondary, 3 tertiary.

The final ranking was made by weighing up the nursing care problems, evidence of the effect of the method, estimated resource consumption, health benefits and the consequences of doing nothing. Since there are no cost calculations for most nursing methods, resource consumption has been estimated on the basis of a combination of the time taken and the staff qualifications required in order to carry out the task.

Care planning is a key area within the nursing care of stroke victims. The phase of illness must always be taken into consideration when prioritisation is made in the planning of the care. For this reason, the group defined four stages: the acute phase, the rehabilitation phase, nursing home/special accommodation and at home. As previously, the same three stages were used in all four phases: 1 basic, 2 secondary, 3 tertiary.

For the prioritisation of support to relatives, the project group chose a similar ranking of the work. Priority 1 indicated basic tasks that were assessed as being mandatory to perform for all relatives; priority 2 included very important work that should to be offered to the majority of relatives, while priority 3 included important work where the requirement is assessed on a case-by-case basis.

The work of the project group was supplemented by a summary of the current situation in the

priority area both in the Swedish health care system and internationally. This compilation is mainly based on the publication “Öppna prioriteringar av hälso- och sjukvård” [Open prioritisation of health care] by the Swedish Society of Medicine. Please see this publication for references to source material<sup>2</sup>.

# Results – model for prioritisation of nursing care

## LITERATURE SEARCH

Despite conducting a search, it was not possible to find any relevant literature regarding prioritisation of nursing care in conjunction with stroke in the Swedish or international scientific literature.

## PRIORITISATION OF NURSING CARE PROBLEMS IN STROKE

The prioritisation criteria developed within the framework for prioritisation by the Swedish Society of Medicine has constituted the starting point for the discussion by the project group about criteria suitable for prioritising nursing care.

The field of nursing care of significance to a stroke victim was identified on the basis of national guidelines for stroke care, the health care programme for stroke in the region of Skåne, the ongoing work within the Swedish Society of Nursing [SSF] with state of the art documentation for nursing care in the case of stroke, various local care programmes and the clinical experience in the project group. In addition to clinical experience, existing nursing research within the areas of communication and stroke, eating and stroke, and pain and stroke<sup>7-12</sup> has formed the basis for the choice of nursing tasks.

Since nursing diagnoses are seldom applied in clinical work in Sweden, the three nurses in the project group instead identified eight significant nursing problems. These were assessed as having serious consequences for the patient if no remedial action was taken. The clinical experience from the care of stroke victims has been important in all discussions on the choice of nursing care problems, nursing methods and in the ranking process.

In an initial stage, identified nursing care problems were ranked on the basis of their degree of urgency – which problems need primarily to be acted upon in the acute phase? This overall ranking (table 1) only gives a general indication of the order in which different nursing care problems in stroke ought to be acted upon.

Table 1. Overall ranking of selected nursing care problems in stroke with associated tasks

<b>Nursing care problems</b>	<b>Nursing tasks</b>	<b>Ranking</b>
Eating difficulties	<ul style="list-style-type: none"> <li>• To ensure nutrition</li> <li>• To adjust food, drink and environment</li> </ul>	1
Diminished bladder and bowel function	<ul style="list-style-type: none"> <li>• To ensure evacuation of the bladder and bowel</li> </ul>	2
Immobilisation	<ul style="list-style-type: none"> <li>• Raising up</li> <li>• To safeguard against risk of falling</li> </ul>	3
Risk of developing pressure sores	<ul style="list-style-type: none"> <li>• To relieve pressure</li> <li>• Skin care</li> </ul>	3
Communication difficulties	<ul style="list-style-type: none"> <li>• To adapt method of approach</li> </ul>	4
Lack of knowledge	<ul style="list-style-type: none"> <li>• To provide information in dialogue with the patient and relatives</li> </ul>	4
Risk of pain	<ul style="list-style-type: none"> <li>• To prevent injury occurring</li> <li>• To relieve pressure</li> </ul>	5
Increased need of rest and sleep	<ul style="list-style-type: none"> <li>• To adjust the care environment</li> <li>• To be allowed to rest</li> </ul>	5

The overall ranking needs to be supplemented with more detailed prioritisations. It is not possible to start with nursing care problems only; the effect of nursing methods and resource requirements must also be factored in – this was the starting point for the project group’s continued work on developing a model for prioritisation of nursing care in stroke.

#### PRIORITISATION OF NURSING CARE INPUT IN THE ACUTE PHASE AFTER A STROKE

A woman of 81, living alone, has had high blood pressure, diabetes and auricular fibrillation for some time. Six years ago, she suffered a minor heart attack.

Now she is taken ill suffering clumsiness in her right hand, then experiencing increasing loss of strength in her right arm and leg. Her speech is becoming slurred and unintelligible. She comes to the hospital by ambulance. During her first day on the ward, a Sunday, she is fully conscious but can only, with great difficulty, answer yes or no to questions. She has a very pronounced paralysis of her whole right arm and a partial paralysis of her right leg. She cannot manage to eat or drink at all by herself; she suffers from urinary incontinence and her blood sugar levels are high. Her closest relative is a daughter who lives overseas – when she is informed of her mother’s serious condition, she requests that her mother should have a room to herself and that a member of staff should constantly be by her side.

During the weekend, staffing in the stroke unit is reduced. Two more seriously ill patients have been admitted during the last 24-hours. Which nursing care requirements should be provided first in this strained situation?

The use of a scale of ten stages, as used in the prioritisation list by the Society of Medicine, proved not to be particularly suitable for prioritising nursing care in this area. The tasks that were prioritised were of a basic nature, which was probably the reason why it was difficult to use all of the stages 1 - 10. As the model for nursing care priorities was developed further, the project group decided instead to try a system of three stages and initially to apply it to nursing care tasks during the acute stage. The work was grouped into three levels: (1) basic, i.e. essential to life, (2) secondary, i.e. important but not essential to life, and (3) tertiary, i.e. less important. Evidence of the effect of this was based partly on the results of research findings. Where there was no scientific basis, the effects were assessed on the basis of clinical experience. Resource consumption was graded into three levels: high, moderate and low consumption. The assessment was based on the competence required, the time spent and the materials consumed. Health benefits of nursing care were based on research findings and clinical experience as well as the assessment of the consequences of nothing being done. As regards the consequences of doing nothing, we have chosen only to report physical and psychological consequences for the patient. If doing nothing results in complications, this will obviously have consequences for the health care system as well as for the patient – the care will be prolonged and become more expensive and there is a risk of increased medicalisation.

Table 2 contains an example of priorities based on nursing care problems and nursing methods, concerning eating difficulties after a stroke, and Table 3 shows tasks concerning diminished bladder and bowel function. Appendix 1 gives an account of corresponding priorities, and their basic data, for other key areas during the acute phase after a stroke:

- Immobilisation
- Risk of developing pressure sores
- Communication difficulties
- Lack of knowledge
- Risk of pain
- Increased need of rest and sleep

Table 2. Example of priorities for nursing tasks: eating difficulties

Nursing care problems	Tasks Basic 1 Secondary 2 Tertiary 3	Evidence of effect	Resource consumption	Health benefit	Consequence of not providing this care
<p>Eating difficulties.</p> <p>Difficulty in swallowing and eating.</p> <p>Lack of interest in food.</p> <p>Perception disruption.</p> <p>Enforced eating.</p> <p>Slowness in eating.</p> <p>Coughing.</p> <p>Leakage.</p>	<ul style="list-style-type: none"> <li>• Guarantee nutrition (1)</li> <li>• Adapt food, drink &amp; environment (1)</li> <li>• Small frequent meals (1)</li> <li>• Adequate sitting position (1)</li> <li>• Practical guidance and supervision (1)</li> <li>• Support aids (1)</li> <li>• Rest before mealtimes (2)</li> <li>• Mouthcare after meals (2)</li> <li>• Oral stimulation (2)</li> <li>• Information/attention to relatives (2)</li> </ul>	<p>Little evidence from case-studies and clinical experience</p>	<p>Moderate</p>	<p>Life sustaining.</p> <p>Strength and stamina for re-habilitation</p>	<p><i>Physical:</i></p> <p>Malnutrition Aspiration Tiredness Pressure sores Infections</p> <p><i>Psychosocial:</i></p> <p>Disorientation/ Depression Personal suffering Hopelessness Isolation</p>

Table 3. Example of priorities for nursing tasks: diminished bladder and bowel function

Nursing care problems	Tasks Basic 1 Secondary 2 Tertiary 3	Evidence of effect	Resource consumption	Health benefit of care	Consequence of not providing this care
Diminished bladder and bowel function. Difficult to control evacuation. Difficult to feel the need. Embarrassment over problems.	<ul style="list-style-type: none"> <li>• To ensure bladder and bowel evacuation (1)</li> <li>• Mobilisation (1)</li> <li>• Incontinence pad (1)</li> <li>• Regular visits to toilet (1)</li> <li>• Plenty to drink (1)</li> <li>• Peace and quiet when visiting toilet (2)</li> <li>• High-fibre diet (2)</li> <li>• Support aids to help with using the toilet (2)</li> <li>• Medication for constipation (2)</li> <li>• Medication for urinary incontinence (3)</li> <li>• Stomach massage (3)</li> </ul>	Clinical experience shows that the work put in has an effect but there is no scientific evidence	Moderate	Increased level of independence  Self-esteem/hope	<i>Physical:</i> Constipation/diarrhoea  Retention of urine/incontinence  <i>Urinary infection (UVI)</i>  Risk of pressure sores  Pain  Dependence  <i>Psychosocial:</i> Confusion  Discomfort  Low self-esteem  Isolation

The project group therefore found it possible to assign priorities among the nursing tasks carried out in stroke. The lack of scientific documentation meant that it was possible in only a few individual cases to refer to basic scientific data in order to assess the value of the work. Instead, the project group chose to assess the strength of clinical experience of the work/method. As these tables and Appendix 1 make clear, it was generally possible to separate the most urgent tasks (priority level 1) from important but not vital tasks (priority level 2). On the other hand, priority level 3 (less important) was used only in a few cases.

### PRIORITISATION OF NURSING INPUT DURING VARIOUS PHASES

A man aged 73 has been nursed in the stroke unit for a cerebral infarction, which has caused paralysis on the left side and serious disruption to his perception/awareness. Speech and memory are not affected. With the aid of the physiotherapist and nursing staff, he has commenced rehabilitation in the intensive care unit for stroke patients and has been able to start walking with the aid of a walking table. Then he was transferred to the geriatric rehabilitation department.

Three weeks after becoming ill, his ability to walk improved further, so that he was tolerably able to move about with a walking stick. The ADL (activities of daily living)

training was assessed as fairly successful but was made more difficult by his diminished perception. Nevertheless, plans were made for discharging him to return home. However, his spouse is suffering from the early stages of dementia and it is expected that the support of the social services will also be required.

From the fourth week after suffering the stroke, the patient's mood worsened. He lost his initiative and could not participate in the rehabilitation programme in the same energetic manner as before, and he mostly wanted to lie in bed. Sleeping became more difficult, he lost his appetite and lost 3 kg in weight over a period of two weeks. He also suffered from constipation.

It was obvious that he was suffering from depression and drug treatment was introduced. However, a number of nursing care problems arose and the question was which of those were most urgent. Should there primarily be a concentration on supportive dialogue [very time-consuming], support with eating, continued planning for returning home, nursing tasks to relieve the constipation, training in physical awareness in order to get to grips with perception difficulties etc? Should anyone, such as a member of nursing staff, be forced to prioritise between these urgent nursing tasks?

The group's assessment was that the nursing tasks would have to be prioritised in various ways, depending on the person suffering, the person's life situation and in which stage of the illness he/she is, i.e. whether he/she is in emergency care, rehabilitation, nursing home/special accommodation or at home. For example, the eating difficulties can be life-threatening in the acute phase because of the risk of aspiration, while someone at home seldom has that same type of eating difficulty. The final level of care is generally decided according to the patient's need of care, which means that there is some similarity in the care needs at one and the same level of care.

In the acute phase of a stroke, nursing care is largely a matter of determining the patient's difficulties, problems and resources in order to prevent complications but also to start early rehabilitation. Basic life-sustaining needs must be met in a dignified and respectful manner.

During the rehabilitation phase, the nursing care focuses primarily on training and adaptation for increased independence. The prevention of complications and provision of support to the individual/family are also given priority.

At the nursing home/special accommodation, nursing care focuses mainly on catering for basic needs and preventing complications. Here too, the utmost endeavours are made to create the conditions for independence in the activities of everyday life. The optimum conditions for a dignified life are created in dialogue with the patient/relatives.

At home, the individual's/family's needs may vary depending on the level of functional impairment, the ability to cope, the health situation of other family members and other resources<sup>13</sup>. A person's living situation may have undergone a dramatic change after suffering a stroke, such as the conditions for coping independently and being self-reliant. For this reason, the

need for care often lasts a long time, sometimes for the rest of a person's life. Their needs can cover anything from people/families with very minor requirements for nursing input, to people/families with extensive needs for nursing input. Studies show the importance of people/families being given the opportunity to play a major part in the rehabilitation process<sup>14</sup>. Prioritisation of nursing care therefore also means supporting, motivating and facilitating the activities of daily life.

We have chosen to concentrate care planning in the areas previously dealt with: eating difficulties, diminished bladder and bowel function, immobilisation, the risk of developing pressure sores, communication difficulties, the risk of pain, increased need for sleep and rest, and the need for knowledge. The needs for nursing interventions often differ during various phases of the illness. The eating difficulties can be life-threatening in the acute phase because of the risk of aspiration, while someone who is at home seldom has that same type of eating difficulty. The final level of care is generally decided on the basis of the patient's need of care, which means that there is a similarity in the need for care within one and the same level of care.

The nursing tasks that are prioritised in Table 4 can form the basis for care planning and the coordination of work in different phases of the illness.

Table 4. Prioritisation of nursing care in different phases of the illness after stroke

<b>Nursing care problems</b>	<b>Nursing tasks during ACUTE PHASE Basic 1 Secondary 2 Tertiary 3</b>	<b>Nursing care during REHABILITATION PHASE</b>	<b>Nursing tasks NURSING HOME/SPECIAL ACCOMMODATION</b>	<b>Nursing tasks at HOME</b>
Eating difficulties	Prevent aspiration.  Ensure intake of nourishment and fluids (1)	Practising swallowing/ eating  Support independence (1)	Ensure intake of nourishment and fluids  Support independence in eating (1)	Give support to adapt consistency and nutritional content to intake (1)
Diminished bladder and bowel function	Prevent retention of urine.  Prevent constipation (1)	Practise bowel and bladder control  Practise independence in activity (1)	Prevent UVI.  Prevent constipation Promote hygiene and well-being (1)	Manage toilet visits independently  Obtain functioning support aids  Promote hygiene and well-being (1)
Immobilisation	Prevent injury/ complications  Practise function (1)	Practise function  Prevent complication (1)	Prevent injury/ complications  Compensate for lack of function (1)	Adapt environment for increased independence  Support aids (1)
Risk of developing pressure sores	Prevent formation (1)	Prevent formation (2)	Prevent formation.  Adapt environment and support aids (1)	Counteract formation (3)
Communication difficulties	Promote basic communication  Make the patient feel confident (1)	Adapt method of approach  Encourage and practise communication (1)	Encourage communication.  Create confidence/sense of security.  Promote communication between patient – relatives – care providers (1)	Make everyday life easier.  Adapt support and help.  Adapt using support aids.  Create confidence (1).
Risk of pain	Prevent formation (1)	Adapt environment and support aids.  Physical awareness training (1)	Prevent formation.  Adapt environment and support aids.  Optimise treatment of pain (2)	Make everyday life easier. Adapt environment and support aids.  Provide support for living with pain Support aids (1)
Increased need of rest and sleep	Adapt care environment (2)	Promote rest and good sleep at night  Adapt times and environment (2).	Prevent turning night into day. Promote relaxing rest and good sleep (3)	Promote rest and good sleep  Adapt environment (3)

## PRIORITISATION OF SUPPORT TO RELATIVES

The significance of providing support to relatives has been highlighted in various ways over the years. To begin with, those highlighted were mainly parents and siblings of children who were suffering from diseases and disabilities or relatives of younger people who were suffering from diseases such as cancer or injuries from road accidents. As an increasing proportion of the population is becoming elderly and suffering from diseases that diminish the ability to manage by themselves, attention must be paid to the importance of support to spouses and other relatives in later phases of their lives.

Close friends and relatives have always provided the majority of all care and nursing in the home. To enable them to manage and be able to continue their important work, it is important that they get support<sup>15-19</sup>. In a two-year monitoring project after stroke<sup>20</sup>, The Swedish National Board of Health and Welfare has commented on “the very high dependence on relatives and close friends that many people suffering from stroke have expressed”. In a more in-depth interview survey of 30 relatives of people who had suffered a stroke<sup>21</sup> two years previously, it emerged that they were all satisfied with the information and support they got in the acute phase at the hospital and at the three meetings for relatives arranged by the stroke unit in the immediate months after the stroke. On the other hand, they did not get the expected follow-up in their primary local authority area.

What do relatives prioritise?

According to the two-year study, relatives requested more information about the consequences of the illness in the long term, including ‘hidden’ disabilities, and contact with other relatives. Those with a heavy burden of care, often 24-hours a day, expressed an urgent need to have free time with some form of respite. Relatives of younger patients requested more varied, individualised support for living together as a family, for their working life and leisure time.

How can support to relatives be prioritised?

Here we have chosen to subdivide the support into three phases:

1. At the hospital
2. In conjunction with discharge
3. After 3-12 months

The need for support varies also with the living conditions of the patient and support can be classified on the basis of:

- relatives of a young patient, who perhaps have small children and are gainfully employed
- relatives of an older patient, who perhaps have other illnesses and functional impairments

Similar to the way in which the interventions for the patient have been ranked, we have chosen to prioritise the work for relatives into three levels:

Priority 1 = basic (mandatory for all)

Priority 2 = very valuable (secondary, offered to the majority)

Priority 3 = valuable (tertiary, assessed on a case-by-case basis)

Table 5. Prioritisation of support to relatives

AT THE HOSPITAL		
	Tasks	Priority
<i>Previously healthy patient</i>		
Relative's need for:		
- information about the course of the illness	Individual information + Support within 24 hours	1
- crisis management	Dialogue with doctors, nurses, counsellors etc during the care period	2
- knowledge about stroke	Access to informational material	2
<i>Previously functionally-impaired patient</i>		
Relative's need for:		
- information and knowledge about stroke	Individual information + support	1
- attention to own work input	Ask questions and document relatives' work input before the illness	2
- contact with other relatives	Meeting with relatives within one month	3
IN CONJUNCTION WITH DISCHARGE		
Relative's need for:		
- follow-up information and knowledge	Individual information + support	1
- contact with relatives	Meetings with relatives 1-2 times, organised by the stroke unit	2
	Contact with local stroke association	3
3-12 MONTHS AFTER BECOMING ILL		
Relative's need for:		
- general follow-up support	Telephone contact with the stroke coordinator at the hospital or in the primary local authority area	1
- special support for special problems, e.g. when needing respite	Contact person in the primary local authority area offers telephone contact	2
- Information and knowledge	Own appointment when visiting the doctor (relative meeting the doctor in private)	3

# Prioritisation in health care - outside factors

The text in this section has been taken, in an adapted, abbreviated version, from the Swedish Society of Medicine document “Öppna prioriteringar av hälso- and sjukvård” [Open prioritisation of health care]<sup>2</sup>, which in turn is based to a large extent on The Swedish National Board of Health and Welfare’s investigation into prioritisation.

## LEGISLATION

When the committee of enquiry, appointed by the Swedish government in 1992 to look into prioritisation within the health care sector, submitted its first report in 1993<sup>22</sup> it contained a thorough review of the ethical problems in relation to prioritisation. This analysis was repeated and reinforced in the committee of enquiry’s final report of 1995<sup>23</sup>, “Vårdens svåra val” [Difficult choices in health care]. The legal preconditions for prioritisation were analysed. In accordance with the Constitution of 1976, Section 1 §2, human dignity should constitute the basis of people’s freedoms and rights: Public authority should be exercised with respect for the equal value of all people and for the freedom(s) and rights of the individual. The legislators have endeavoured to conform to the UN Declaration on Human Rights of 1948, a declaration that Sweden ratified. One conclusion was that prioritisation ought to be an open process, based on a generally accepted set of fundamental values.

The Swedish Parliament passed a resolution in 1996 (1996/97:60) concerning guidelines for prioritisation within the health care system. The Parliamentary resolution means that, since 1 July 1997, there is a general prioritisation rule in § 2 of the Swedish Health Care Act which establishes that the person in greatest need of health care should be given priority. The preparatory work for the Swedish Health Care Act provides the reader with insight into the legislators’ attitude towards prioritisation: a principal element is that the need for health care should guide the opportunities of receiving care within the framework of the financial resources that the responsible authority has at its disposal. This also covers the fact that, when prioritising between two patients, the person who is in most need of care should be given preference. Society must ensure that – within the framework of available resources and competence – care is offered to all in need of care. It is particularly urgent for society to ensure that certain groups with low levels of autonomy, such as the elderly, the disabled and children, have their needs assessed.

The Health Care Act is framework legislation and thus allows great scope for the health care authorities, and to a certain extent, also members of health care staff to interpret the law.

The Bill describes certain nationally established general guidelines that ought to be followed

when prioritising. The prioritisation guidelines are based on the previously reported ethical principles and are exemplified in broad prioritisation groups. According to the Parliamentary resolution, priorities within health care ought to be based on an ethical platform consisting of three fundamental principles, which are:

- The principle of human dignity according to which all people are of equal value and have the same rights regardless of personal characteristics and functions in society
- The principle of need and solidarity in accordance with which the resources ought to be concentrated on the areas [activities, individuals] of greatest need
- The principle of cost-effectiveness in accordance with which efforts should be made to ensure a reasonable relationship between costs and outcome, measured in quality of health and life, when choosing between different activities or interventions

These three ethical prioritisation principles are described in more detail in Appendix 3. In short, according to the principle of human dignity, all people have the same right of access to health care, regardless of age, sex and social position. This does not exclude the possibility of a change in the focus of care, e.g. that for very old people, greater emphasis is placed on raising the quality of life rather than prolonging it. There is great support among the Swedish public for the principle of need/solidarity: the person whose need is greatest should get most attention. However, one problem is, just what is meant by the term “need” and who defines that need? Is it the patient him- or herself, or someone else? If it is the patient, how can a true need be differentiated from demand without a substantial true need? For assessments in accordance with the principle of cost-effectiveness, reliable basic scientific data is often required. For this reason, the principle will be difficult to apply in areas of health care where there is little scientific data. It is consistent with these ethical basic principles, in individual cases, to take into consideration the fact that the benefit from health care might be limited.

The principles are ranked so that the principle of human dignity comes before the principle of need/solidarity, which, in turn, comes before the principle of cost-effectiveness [serious illnesses come before those that are less severe, even if the care of the more serious condition costs considerably more]. On the basis of these ethical principles, certain rough guidelines were established in the Bill on prioritisation for assigning priorities in health care, subdivided into four priority groups based on level of urgency. These are:

#### Prioritisation group (1)

Care during life-threatening acute illnesses

Care of patients with diseases that would lead to a lasting debilitating condition or premature death if left without treatment

Care of patients with serious chronic diseases

Palliative care and care in the final stages of life

Care of people with diminished autonomy

Prioritisation group II Prevention

Habilitation/rehabilitation

Prioritisation group III

Care of less serious acute and chronic diseases

Prioritisation group IV

Care for reasons other than disease or injury

The guidelines comprise a number of broad groups with clinical examples. It is stressed that these are just examples and that the need for care must be assessed, individually in each case, on the basis of the needs of the patient concerned. For a specific disease, the need for and effect of different nursing tasks may change over time – a specific disease can therefore be inserted under several different prioritisation groups.

#### WORK ON PRIORITISATION AT A NATIONAL LEVEL IN SWEDEN

The prioritisation delegation, which had the task of spreading information and knowledge about the Parliamentary resolution on prioritisation in health care, submitted its report to the government in 2001. The report makes it clear that the main responsibility for taking the prioritisation process further lies with the health care authorities. In its supervisory capacity the Swedish National Board of Health and Welfare has the task of ensuring that the Parliamentary resolution is adhered to. Interested organisations at national level [primarily the Swedish Association of Local Authorities and Federation of County Councils] play central roles in the work. Development work must be intensified in order to produce relevant, comparable measurement and follow-up data.

The Swedish National Board of Health and Welfare introduced a long-term project in 1999 to develop methods for applying the Parliamentary resolution on prioritisation to the health care sector. The national action plan for the development of the health care service [Bill 1999/2000:149] includes the statement that the work of the Swedish National Board of Health and Welfare is to ensure that the long-term objective of prioritisation is integrated into the planning work at all levels by the health care authorities, resulting in deliberate and open prioritisation. In conformity with the special agreement between the state and county councils concerning funding of health care services [the Dagmar agreement from the year 2000 onwards], the Swedish National Board of Health and Welfare also has the task of developing decision-making support for prioritisation within the framework of the guidelines for the care and treatment of patients with chronic diseases.

Special surveys have been carried out to highlight the way in which the prioritisation resolution can and ought to be applied within defined areas. One survey has been carried out concerning prioritisation in the event of involuntary childlessness (SoS report 1998:8) and one on prioritisation in the case of testing hearing aids (SoS report 1999:18).

Over the last two years, the work of the Swedish National Board of Health and Welfare on prioritisation has focused on drawing up basic knowledge data to support prioritisation decisions by the health care authorities. Guidelines for cardiac care and for the care of patients with asthma and chronic obstructive pulmonary disease [COPD] and venous thrombo-embolism [blood clot disease] have been circulated for comment, and publication is estimated to be in spring 2004. The work on guidelines for stroke care and for patients with the most common forms of cancer is continuing. The Prioritisation Centre in Linköping has been commissioned by the Swedish National Board of Health and Welfare to follow up the implementation of the guidelines for cardiac care during the period 2003 – 2005.

The purpose of the work of the Swedish National Board of Health and Welfare on guidelines for care and treatment is to contribute to increased efficiency and fairness in health care both within and between disease groups and to a more needs-controlled health care service. Above all, the work focuses on ranking within a disease group [known as vertical prioritisation] but in the long term it could be used for comparisons between disease groups [horizontal prioritisation].

In Sweden, *Läkemedelsförmånsnämnden* [the Pharmaceutical Benefits Board] was established in October 2002 with the task of establishing pricing and deciding on subsidies for out-patient medication. The task does not just apply to new drugs – the Pharmaceutical Benefits Board is to review the entire range of drugs. The Board's work entails a prioritisation of the drugs that are to be subsidised through public funding.

In autumn 2000, Östergötland County Council formed a National Competence Centre for prioritisation within the fields of health and welfare – the Prioritisation Centre. The Swedish Ministry of Health and Social Affairs, the Federation of County Councils and the Swedish Association of Local Authorities collectively gave Östergötland County Council the task of contributing to the development of methods to support open prioritisation. The Prioritisation Centre is to carry out research and development but also to contribute to the transfer of competence between research and health care and social welfare in practice, and the exchange of experience between people working within these fields, elected representatives, as well as organisations and the general public. The current task will continue to the end of 2004. A planned evaluation is to form the basis for deciding on its possible continuation.

## MEDICAL PROGRAMME WORK AND PRIORITISATION IN THE COUNTY COUNCILS

Certain county councils have examples of systematic work concerning prioritisation or at least good efforts. Some of these examples are shown below.

- Östergötland County Council has since the mid-1990s been working on medical programmes aimed at creating a better basis for open prioritisation. In autumn 2003, this work resulted in the first open vertical and horizontal prioritisations, in the form of a list of a number of medical conditions and actions that the county council will not finance if there is a shortage of resources. The proposal has given rise to a major political and mass-media debate.
- In the county of Västergötland, wide-ranging work is currently ongoing to develop a common

basis for regional vertical prioritisation within most specialities.

- As early as 1992, county council delegates in the county of Västerbotten adopted a common county council prioritisation programme. In recent years, knowledge has been gathered concerning the needs of health care for different groups of patients in three areas: diabetes, depression and coronary diseases. The purpose of the programme is to improve knowledge and thereby provide boards and county council administrations with better basic data when prioritising and distributing resources.
- Some hospitals and health centres are working on prioritisation. Examples of this include the health centres in Östersund, the Sundet Health Centre in Härnösand and the Sundsvall Hospital, where extensive prioritisation work is the basis for forming and distributing operation teams between specialities at the central operation theatre.

## THE WORK OF THE SWEDISH SOCIETY OF MEDICINE ON PRIORITISATION

During the last three years, the Swedish Society of Medicine has been involved in issues concerning prioritisation in health care. The Society of Medicine's assessment has been that a shortage of resources [money, staff] and increasing needs [medical advances, ageing population] is forcing prioritisation to be made in Swedish health care, limiting the range of care available. According to the Society of Medicine, only health care staff are able to provide the basic data needed when politicians have to make priorities. The people who actively run the health care services are best suited to describe the consequences that result from a lack of treatment.

Eight sections of the Society of Medicine have been working on producing vertical prioritisation lists. The Society of Medicine's objective is that all specialities through their sections should produce prioritisation lists in accordance with the model produced. Primarily, the lists produced should be used for assistance in internal work locally in health care.

The model for prioritisation prepared by the Society of Medicine has recently been presented in the publication "Öppna prioriteringar av hälso- och sjukvård" [Open prioritisation of health care]<sup>2</sup>. Each speciality has prepared a system of ranking with regard to Diagnosis/Intervention, Health Benefit/Advantage, Cost/Resource, Health Benefit/Advantage based on Medical Outcome, Risk and Quality of Life. After that, priorities have been assigned comprehensively on a scale of 10 stages. The highest priority is given to an immediately life-threatening condition and lowest are conditions that do not entail any risk of increased morbidity, decreased level of function or diminished quality of life.

Through the work of the participating sections, which each represent a medical speciality, the Society of Medicine has drawn up a model of how priorities can be assigned. The Society of Medicine's objective is for all specialities, primarily those in clinical care, through their sections to produce prioritisation lists in accordance with the model proposed. The model has not yet been fully developed and allows room for detailed solutions based on the specialities. The exchange of experiences will continue to be a major requirement in the future. Primarily, the vertical lists are intended to be used to assist the internal work by the respective county councils.

## OPEN PRIORITISATION WORK IN OTHER COUNTRIES

Several countries, like Sweden, have developed national principles and guidelines for prioritisation within the health care services. Norway was the first country in the West to establish national guidelines for prioritisation within the health care services. As early as 1987, a Government committee – called the *Lønningutvalget*<sup>24</sup> – introduced a proposal for “Guidelines for prioritisation within health care”. In 1996, the Norwegian government initiated a new national prioritisation enquiry called *Lønning II*<sup>25</sup>. Apart from the fact that there is a collective set of basic values that has attracted attention, relatively little has happened in Norway as regards creating open prioritisation. The most concrete thing is the fact that a national prioritisation committee has been set up to act as adviser to the government.

In the American state of Oregon, there was a prioritisation reform at the end of the 1980s. The objective was to develop insurance cover that could provide access to fundamental health care for all Oregon residents whose incomes fall below the federal poverty limit, and certain other uninsured groups. This was to be achieved by limiting the scope and width of the range of health care services while also making the basic range available to more people. This was the first more comprehensive example of an attempt to use scientific facts and to establish priorities in the population by entering into a dialogue with the general public.

In the Netherlands, the Dunning committee was given the task of proposing the principles that should determine the content of the basic insurance system that covers 95% of the publicly financed range of health care services. Four prioritisation principles were settled on, which must all be fulfilled if a medical procedure is to be covered by the basic insurance: The work must be necessary, documented as efficient and sufficiently cost-effective, and in addition the condition and work must be such that the liability cannot be transferred to the individual. The Government’s efforts to define a basic package of health care services that should be guaranteed for all, encountered political difficulties and has not been completed.

In New Zealand, in 1992, a prioritisation committee was set up, with the task of producing annual recommendations, concerning the basic health care services that ought to be financed using public funding. Today the committee has a more limited function than was first envisaged. Here too the ambitions of bringing about open prioritisation have encountered resistance from various interested parties, which has been politically embarrassing for the governing party.

The clearest and most successful international trend is the introduction of open prioritisation of new drugs via a subsidies resolution linked to a review of basic scientific data with regard to clinical effect and cost-effectiveness. Such systems have been in existence since 1992 in Australia and New Zealand.

# Summarising discussion

## OPEN OR CLOSED PRIORITISATIONS?

It is easy to be in agreement on the basic principle that prioritisation within the health care services ought to be open and transparent. Open prioritisation means that the basic reasons for the prioritisation made are reported as well as which tasks are ranked high and low among those that the publicly financed health care system is to cover. This is so that all interested parties – the general public, patients, decision-makers and health care staff – are kept informed and are given the opportunity to influence the way priorities are assigned.

The alternative to openness is for prioritisation to take place in secrecy. In the debate that followed on from the Östergötland County Council presentation of prioritisation lists, certain politicians and certain representatives of the health care professions maintained that the full prioritisation process could not take place openly. It is indeed possible to accept certain fundamental ethical principles for prioritisation. But it is stressed that the actual prioritisations are still best handled in confidential conversations between the health care staff and the patient. To openly down-rank parts of what is included in today's health care system would produce unfairness – it would no longer be possible to fulfil the objective of care for all on equal terms.

This reasoning may sound sympathetic but it leaves room for arbitrariness. This does not take into consideration the actual situation that the resources in Swedish health care will not cover everything that the care staff could accomplish or everything that the patients and their relatives might request. In a closed system of prioritisation, those who can shout loudest can further their interests more easily. If anything, it is preparing the ground for unfairness in health care. The strong help themselves, be it a matter of individual patients, organisations or representatives of a health care speciality. If the resources are very limited, closed prioritisation runs the risk of leading to a health care system on unequal terms. A common misunderstanding is that no consideration is given in systems with open prioritisation to the fact that needs vary among patients with one and the same diagnosis. As long as the needs of the individual patient can be made clear, they are included as an important part of the open prioritisation process.

A system without open prioritisation and impact analyses might mean that it is only afterwards that it is discovered which prioritisations have actually been made. Reallocation has taken place in health care leading to more resources being allocated to drugs and high-tech equipment and less to nursing care<sup>1</sup>. These changes were not made using open prioritisation, nor was there any accounting for the possible consequences of these decisions leading to reallocation of resources.

A system of open prioritisations reduces the risk of arbitrariness and the unintentional reallocation of resources. However, it leads to the non-implementation of certain tasks that the health care system could perform if the resources were unlimited. This situation is not new; at least as regards the time available, health care staff have constantly prioritised – however often unclearly, and unaccounted for.

#### IS IT POSSIBLE TO IMPLEMENT OPEN PRIORITISATIONS WITHIN NURSING CARE?

In the review of the literature that was included in this project, it was not possible to identify any previous scientific publications within the field of prioritisation in nursing care. An ideas and discussion publication, issued by the SSF and SPRI [Swedish Institute of Health Services Development]<sup>26</sup> contains a discussion of the daily prioritisations that are made in nursing care. This describes a number of ethical problems faced when provision of care and welfare are described. The authors wish to create awareness that the choices made and the stand taken are based on our values. It is worth noting the fact that very little attention has been given to prioritisation in nursing care, considering the fact that prioritisation in other parts of the health care system has been given so much attention. One reason might be that all nursing care is viewed as so basic that no prioritisation is possible. It is the view of the project group that this perspective leads to people evading the problem. There is a risk that the resources are not used optimally if the setting of priorities is not made clear. Unless the consequences of different prioritisations are made transparent, there is a risk that nursing care [perhaps unintentionally] is down-prioritised.

To judge from the review of the literature, this pilot project is a pioneering work. The project has shown that it is possible to assign priorities in the field of nursing care in a defined area. However, the project and its results have important limitations:

- It just concerns one field, nursing care in the case of stroke. This field was chosen because it affects a lot of patients who are highly dependent on care; the nursing care is extensive and relatively well defined, with a certain amount of scientific data on outcome. Although a lot of the nursing care given to patients with stroke is also highly applicable to other groups of patients, there is still some doubt about just how possible it is to generalise about our model for prioritisation. Limiting it to stroke also means that our proposals do not give any guidance about the way in which horizontal prioritisation could be made in nursing care, i.e. weighing up nursing care for different disease groups against one another.
- The proposals for prioritisation have mainly been discussed by the project group and it is uncertain how established these may be among health care staff and decision-makers. This report should be viewed as a basis for continued discussions about open prioritisation within the field of nursing care.
- The scientific basis for determining the effectiveness of nursing care and its consumption of resources is very fragile.
- Although the proposals are largely founded on the extensive clinical experience of stroke

care represented in the project group, the proposed prioritisations have not been tested in practice; can the prioritisations be applied and what impact will they have on routine health care? These questions should be answered urgently for all of the prioritisation lists presented to date, nationally and internationally.

## IS IT POSSIBLE TO ASSESS HEALTH ECONOMICS?

Health economics plays a predominantly large role in prioritisation in other areas of health care. Health-economic evaluations of nursing methods have not previously been common. Such a process means identifying, measuring, assessing and comparing costs and effects of alternative methods. When the condition of a patient can be measured before and after treatment, it ought to be possible to evaluate the work from a health-economic perspective.

There are different techniques for making a health-economic assessment. A cost-benefit analysis is used in health care when more than one effect is of interest, e.g. both quality of life and the years of life gained.

It is interesting to make comparisons of costs and effects within the nursing field but also between nursing methods and other methods used in health care. Evaluation of nursing care is therefore needed for several reasons. Partly to evaluate whether the nursing care is the most appropriate, partly to compare costs and effects of nursing care with, for example, costs and effects of work of a technical and medical nature.

The conclusion is that in nursing today it is rarely possible to make conventional analyses on a health-economic basis, where there is a shortage of basic scientific data for assessing the benefits and the costs of methods. There is therefore great potential for scientific development.

## HOW ARE NEEDS ASSESSED?

The prioritisation document presented by the Society of Medicine is based on pairings of diagnoses– interventions. However, this has often been perceived by clinics as much too unrefined. Most doctors wish to base their decisions on unique conditions of the patient, above all, the seriousness of the condition: more serious conditions must have priority over those that are less serious within the same diagnosis group. Many of the lists of priorities that the section of the Society of Medicine presented therefore also contain a grading of need on the basis of the level of seriousness of the disease. This has the disadvantage that lists of priorities risk being very detailed and complex, which in turn means that their applicability may be reduced.

In the work on nursing prioritisation, it became clear at an early stage that it was more appropriate to start from “needs/problems” rather than “diagnosis”. The term “need” can have many meanings and it must be clearly differentiated from “demand”. Many people with a high level of need cannot express this clearly and, on the other hand, many others with a low level of need can demand a great deal of care. It must be the task of health care staff, after consultation with the patient and sometimes with relatives, finally to assess the level of need. Individual factors must carry weight in this assessment. In order to be able to make open prioritisations it is

important to be able to describe clearly how the assessments were made.

# Future perspectives

Since we have not been able to find any previous projects on the prioritisation of nursing care, the only grounds we have had to rely on in our work has been the experience gained when drawing up guidelines for purely medical prioritisations. Our model for prioritising nursing interventions within stroke care must therefore be regarded as very preliminary. This report constitutes the basis for a discussion that might stimulate development of more definitive models. The project group's desire for continued development in the field covers the following:

- The model will be presented broadly to health care staff within the nursing field and other parts of the health care service. This will take place by distributing this report, publishing articles in specialist journals [nationally and internationally] and giving presentations at conferences, staff meetings etc.
- The model will be discussed among those working clinically within nursing care, and among researchers and doctors as well as within professional organisations, including decision-makers within the Swedish health care service [county councils, private care and the national authorities], patient organisations and in the public debate. The professional organisations (SSF and *Vårdförbundet*, the Swedish Association of Health Professionals) will be responsible for leading the discussion.
- The model will be modified on the basis of this type of broad discussion, and a more established model for prioritisation will be adopted by the SSF and the Swedish Association of Health Professionals.
- On the basis of a modified model for stroke nursing, the professional organisations are drawing up a more general model for prioritising nursing methods that apply to all nursing care problems. This general model will then be applied to individual medical diagnoses in vertical prioritisation.

A long-term goal might also be to produce basic data for making horizontal prioritisations within nursing care, i.e. to compare nursing care methods between different medical diagnoses. Another long-term goal is to integrate prioritisation of nursing care methods with the prioritisation of methods within all types of health care, mainly preventive care, medical care and rehabilitation.

# Bibliography

- Anell & Hjortsberg C. (2001). Omstruktureringen av vården – störst konsekvenser för de äldre. *Läkartidningen*, 98, 560-564.
- Axelsson K (1988). Eating problems and nutritional status after stroke. Umeå University Medical Dissertations, New Series No 218.
- Bendz M (2000). Rules of relevance after a stroke. *Soc Sci & Med*, 51, 713-723.
- Grant J & Davis L (1997). Living with loss: the stroke family caregiver. *J Fam Nurse*, 13, 21-36.
- Hulter Åsberg K, Johansson L. Två år med stroke ur ett anhörigperspektiv. *Socmed tidskrift* 2002;2:146-152
- Jacobsson C (2000). Eating training after stroke and its cost-effectiveness. Umeå University Medical Dissertations, New Series No 688.
- Kirkewold M (2003). Familjens ställning i omvårdnaden. I Kirkevold M & Strömsnes
- Ekern K (red). Familjen ett omvårdnadsperspektiv. Göteborg, Liber.
- Lövgren G, Engström B, Norberg A (1996). Patients' narratives concerning good and bad caring. *Scand J Caring Sci* 10, 151-156.
- Low T S, Payne S & Roderick P (1999). The impact of stroke on informal carers: a literature review. *Soc Sci Med*, 49, 711-725.
- Nilsson I, Axelsson K, Gustavsson Y, Lundman B & Norberg A (2001). Well-being, sense of coherence, and burn out in stroke victims and spouses during the first few months after stroke. *Scand J Caring Sci*, 15, 203-214.
- Norberg A, Engström B, Nilsson L (1994). God omvårdnad. Grundvärderingar. Falköping, Bonnier. NOU 1987:23 NOU 1997:18
- Nydevik I & Eller B (1994). Stroke patient in long term care. *Scand J Caring Sci*, 8, 155-161.
- Secret (2000). van der Smagt. Duijnstee, Hamers & Huijer Abu-Saad (2000).
- SOU 1993:93, Vårdens svåra val. Rapport från utredningen om prioriteringar inom hälso- och sjukvården, Stockholm 1993
- SOU 1995:5 Vårdens svåra val. Slutbetänkande av prioriteringsutredningen, Stockholm 1995
- Socialstyrelsen – att drabbas av stroke. Hur ser situationen ut två år efter insjuknandet? Äldreuppdraget 2000:13.
- Sundin K (2001). Sense of 'understanding and being understood' in the care of patients with communication difficulties. Umeå University Medical Dissertations, New Series No 699.
- Svensk sjuksköterskeförening, Stockholm (2002). Omvårdnad som akademiskt ämne SSF och SPRI (1998). Det goda valet – prioriteringar i omvårdnad Nr 5, Stockholm, SPRI:s förlag.

Svenska Läkaresällskapet, Stockholm (2004). Öppna prioriteringar av hälso- och sjukvård. Slutrapport från Svenska Läkaresällskapetets prioriteringskommitté.

Waldau S (2001). Prioritering i hälso- och sjukvården – att hushålla för rättvisa. Lund, Studentlitteratur.

Westergren A (2001). Eating difficulties in elderly, focusing on patients with stroke. Bulletin No. 9, Department of Nursing, Medical Faculty Lund University, Sweden.

Widar M (2003). Living with long-term pain after a stroke. Linköping University Medical Dissertations, No 827. Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences. Linköping University, Sweden.

Willman A, Forsberg A, Strömberg A (2003). Metoder i omvårdnad och i sjuksköterskans arbetet. Svensk sjuksköterskeförening, Stockholm.

# Appendices

## APPENDIX 1: NURSING CARE IN THE ACUTE PHASE AFTER SUFFERING A STROKE

Page 13 gives an account of two examples of the way in which nursing care can be prioritised. These examples apply to eating difficulties and diminished bladder and bowel function after a stroke. This shows the prioritisation lists that the project group drew up for other key areas within the nursing care for stroke victims during the acute phase.

Table 6. Prioritisation of nursing tasks in the event of immobilisation

Nursing problems	Tasks Basic 1 Secondary 2 Tertiary 3	Evidence of effect	Resource consumption	Health benefit of the work	Consequence of not providing this care
Immobilisation  Reduced mobility, dizziness and difficulties with balance	<ul style="list-style-type: none"> <li>• Raising up (1)</li> <li>• To safeguard against risk of falling</li> <li>• Turning (1)</li> <li>• Mobility (1)</li> <li>• Assistance with moving (1)</li> <li>• Maintaining suppleness (1)</li> <li>Adapt environment (2)</li> <li>• Support aids (2)</li> <li>• Balance practice (2)</li> <li>• Strength training (2)</li> <li>• Information/attention to relatives (2)</li> </ul>	Certain evidence of hip protection from intervention studies	Major	Reduced risk of complications. Increased independence  Self-esteem/hope. Improved rehabilitation	<i>Physical:</i> Risk of falling/ fracture Contractures.  Risk of deep vein thrombosis. Constipation Pulmonary embolism Pneumonia Spasticity Pain Pressure sores  Difficulties managing ADL  <i>Psychosocial:</i> Dependence Low self-esteem

Table 7. Prioritisation of nursing tasks in the event of a risk of developing pressure sores

<b>Nursing problems</b>	<b>Tasks</b> <b>Basic 1</b> <b>Secondary 2</b> <b>Tertiary 3</b>	<b>Evidence of effect</b>	<b>Resource consumption</b>	<b>Health benefit of the work</b>	<b>Consequence of not providing this care</b>
<p>Risk of developing pressure sores</p> <p>Need help in moving about and changing position, those in wheelchairs or lying in bed slide down in the chair or bed, diminished sensitivity, eating difficulties, incontinent</p>	<ul style="list-style-type: none"> <li>• To relieve pressure (1)</li> <li>• Skin care (1)</li> <li>• Guaranteed nutrition (1)</li> <li>• Adaptation of underlying surface (smooth, cool, dry) (1)</li> <li>• Lowering of raised body temperature (2)</li> </ul>	<p>There is evidence from randomised studies</p>	<p>Moderate</p>	<p>Stamina/ strength and energy for rehabilitation</p>	<p><i>Physical:</i></p> <p>Pressure sores</p> <p>Severe pain</p> <p>Worsened mobility and rehabilitation</p> <p><i>Psychosocial:</i></p> <p>Personal suffering</p> <p>Isolation</p>

Table 8. Prioritisation of nursing tasks in the event of communications difficulties

<b>Nursing problems</b>	<b>Tasks</b> <b>Basic 1</b> <b>Secondary 2</b> <b>Tertiary 3</b>	<b>Evidence of effect</b>	<b>Resource consumption</b>	<b>Health benefit of the work</b>	<b>Consequence of not providing this care</b>
<p>Communication difficulties</p> <p>Difficulties in understanding</p> <p>Difficulties in making oneself understood</p>	<ul style="list-style-type: none"> <li>• Adapt method of approach (1)</li> <li>• Attentiveness to the person (1)</li> <li>• Allow time/ wait for answers (1)</li> <li>• Continuity in carer relationship (1)</li> <li>• Encouragement/ support(2)</li> <li>• Support aids (2)</li> <li>• Information/ attention to relatives (2)</li> </ul>	<p>Little evidence from observation studies and clinical experience</p>	<p>Major</p>	<p>Increased independence</p> <p>Self-esteem/ hope</p>	<p><i>Psychosocial:</i></p> <p>Difficulties in expressing needs/requirements</p> <p>Difficulties in being understood</p> <p>Dependency</p> <p>Dejection</p> <p>Confusion</p> <p>Hopelessness</p>

Table 9. Prioritisation of nursing tasks in the event of lack of knowledge

<b>Nursing problems</b>	<b>Tasks</b> Basic 1 Secondary 2 Tertiary 3	<b>Evidence of effect</b>	<b>Resource consumption</b>	<b>Health benefit of the work</b>	<b>Consequence of not proving this care</b>
Lack of knowledge What will happen?	<ul style="list-style-type: none"> <li>In dialogue to give information to the patient/ relatives for understanding of the situation (1)</li> </ul>	Lack of scientific evidence from "stroke – schools"	Moderate	Conditions for managing alone, greater independence, manageability and well-being	<i>Psychosocial:</i> Uncertainty Disquiet/fear Reduced cooperativeness in care and treatment Unrealistic expectations

Table 10. Prioritisation of nursing tasks where there is a risk of pain

<b>Nursing problems</b>	<b>Tasks</b> Basic 1 Secondary 2 Tertiary 3	<b>Evidence of effect</b>	<b>Resource consumption</b>	<b>Health benefit of the work</b>	<b>Consequence of not providing this care</b>
Risk of painful condition Local pain in shoulders (nociceptive pain) Disturbed/ distorted sensitivity, discomfort and pain (central post-stroke-pain) Tension headache	<ul style="list-style-type: none"> <li>To prevent injury (1)</li> <li>To relieve pressure (1)</li> <li>To facilitate a symmetrical position of the body (1)</li> <li>Adaptation in conjunction with ADL (1)</li> <li>Attentiveness to cold/ heat/ movement(1)</li> <li>Relaxation/ resting positions (2)</li> <li>Medication (2)</li> </ul>	There is clinical experience of positive outcome	Small	Stamina/ strength for rehabilitation Motivation Independence Well-being	<i>Physical:</i> Fatigue Sleeping problems Immobilisation Diminished stamina <i>Psychosocial:</i> Dependency Negative impact on moods Depression/ low spirits Reduced motivation Personal suffering

Table 11. Prioritisation of nursing tasks where there is a risk of an increased need of rest and sleep

Nursing problems	Tasks Basic 1 Secondary 2 Tertiary 3	Evidence of effect	Resource consumption	Health benefit of the work	Consequence of not providing this care
Increased need of rest and sleep. Tiredness and confusion.	<ul style="list-style-type: none"> <li>• To adapt the care environment (2)</li> <li>• To be allowed to rest (2)</li> <li>• Resting positions (2)</li> <li>• Medication (2)</li> <li>• Relaxation (3)</li> </ul>	There is clinical experience	Small	Stamina/ strength for rehabilitation. Vitality/ hope. Mental strength.	<i>Physical:</i> Risk of falling Tiredness Pain  <i>Psychosocial:</i> Confusion  Diminished concentration

## APPENDIX 2: CARE PLANNING

Stroke frequently means a lifelong disability. The way of life is changed as are the conditions for managing independently. Everyday life makes various demands on the individual depending on whether the person is of working age or a senior citizen, or whether the person lives alone or with others. These are the factors that have to be taken into account when drawing up a care plan.

Care planning in hospital normally means planning the care and assistance the patient is going to need after discharge – based on need. The need might concern social planning, training, support aids, nursing activities, medical treatment and monitoring. Planning can cover work input from various professional groups. The resource input may be distributed between the municipal authorities and county councils.

Care planning deals with the planning of future care, which can be difficult to foresee at an early stage of the illness or when the patient is still in hospital – for this reason, the plan should constantly be reviewed as needs change.

Care planning should cover:

- *Medical monitoring* Monitoring of medication, prevention and treatment, if needed, of complications of stroke, treatment of risk factors and measures to prevent suffering a new stroke. There may be a need for assistance with medication, taking specimens or injections and a need for information on how to attain better health.
- *Rehabilitation and exercise* An assessment of the need for different types of rehabilitation. In later stages, forming an opinion on the need for exercises to maintain function.
- *Social planning* Type of accommodation and adaptation of the home might be required, as well as relieving the pressure on relatives. This might concern a need for transportation services, an official representative to look after welfare rights, alarm, assistance with cleaning or support in a new life situation.

- *Personal care* Help or supervision with hygiene, clothing, moving about, using the bathroom and food.

Clear targets ought to be set for the care, and responsibility for the different tasks ought to be clarified. There is a risk that function failure increases gradually, after which renewed exercise work may be necessary. Frequently, stroke produces a life-long disability, a change in the life situation, and the patient will need long-term support.

Inadequate planning or inadequate input of nursing care after stroke can produce consequences such as insecurity, complications, increased disability and dependence on assistance, which often requires increased input from the health care system. One of the problems is that responsibility is often shared by various professional categories and by various responsible authorities resulting in an inadequate holistic view. In addition, care planning in hospital often carried out by hospital staff and the local authority's representative, which makes it difficult to plan the total input needed. It is also difficult to foresee problems which the home environment and the life situation might entail.

### APPENDIX 3: COMMENTS CONCERNING FUNDAMENTAL PRIORITISATION PRINCIPLES

As introduced on page 22, the prioritisation committee's final report "Vårdens svåra val" [Difficult choices in care] (SOU 1995:5) established an ethical platform for prioritisation within the health care system. The three prioritisation principles, which were then adopted by the Swedish Parliament, are commented on briefly in this appendix.

#### The principle of human dignity

The fundamental principle that all people are of equal value and have the same rights means, for example, that age, sex, social position or dependency shall not determine whether or not a person should receive care.

This principle may appear straightforward, simple and easy to accept. However, it is not always in line with what many people consider to be fair. The principle means, for example, that an elderly serious substance abuser would get priority, ahead of a single woman with three children, for a place in the cardiac intensive care department if the suspicion of cardiac arrest is greater in the substance abuser.

The human dignity principle also means that it does not matter whether or not the illness is self-inflicted. A smoker with serious lung disease has the same right to care as a non-smoker. However, whether or not the outcome of treatment is clearly dependent on whether the unhealthy

lifestyle continues (for example, the outcome of an operation for vascular constriction in the leg is clearly worse in a smoker), a purely medical assessment might mean that the issue of lifestyle still has a place in the prioritisation.

Neither is age an easy matter to manage from the prioritisation perspective. Often the medical outcome of treatment is worse and the risks greater in the elderly, which means that for purely medical reasons the choice is made to abandon treatment. In that case, instead, more concentration can be given to support and nursing care – the resources that are invested may be just as great as in younger people but they have a different focus. In younger people, the emphasis is often on work to prolong life, in the elderly it is instead on work to improve the quality of life. On the other hand, to establish indication limits strictly on the basis of chronological age does not conform to the principle of human dignity.

According to the attitudes survey that was presented in the Prioritisation Committee's final report, and according to the views that have emerged during the years since the Parliamentary resolution, the human dignity principle does not appear to be obvious to everyone, neither among the general public, politicians or doctors. This probably requires a more in-depth discussion among the general public and among the care representatives and those with political responsibility for the apparently self-evident principle of human dignity is to gain full acceptance or be modified.

#### The need-solidarity principle

This prioritisation principle means that health care resources should be allocated to those in greatest need. Those whose need is less may have to stand back, e.g. they do not gain access to all the care they themselves consider they need or because the health service becomes less accessible for them in other respects (= solidarity with the people in greatest need).

The key term is “need”. Who defines the need and what criteria is it based on? It would be simplest to say that the person seeking care can him/herself best determine what his/her needs are. This would be to respect the individual's autonomy and be well in line with the objectives of greater patient influence and the requirements for consultation with the patient that are established in a Parliamentary resolution of 1999. A recommendation by the Swedish Federation of County Councils, regarding the right of a person, under certain circumstances, to seek care in another county council area than his or her own, supports the perception that the patient is the person best able to define his or her needs.

But this perception of what “need” means, equates need with demand. The prioritisation committee rejected the fact that demand should control prioritisation within health care. Among other things, it was seen how many patients with diminished autonomy and serious illnesses, such as those with dementia or psychosis, would find it difficult to make their needs known within a health care system based on demand. Instead, “need” was discussed on the basis of a combination of two other definitions:

- *Suffering and threat to life* Who run the greatest risk of dying, of suffering serious complications? Who have the greatest impairment of physical, mental or social function? Which factors have the greatest impact on quality of life?
- *Suitability for intervention* There is no need for an intervention that has little prospect of helping the patient, although the illness would be very serious. Sometimes, there may be a greater need for nursing care with assured outcomes than for surgical or medical interventions with little prospect of benefit to the patient.

### The cost-effectiveness principle

The final report of the prioritisation committee formulates this principle thus: “when choosing between different areas of activity or interventions, an endeavour should be made to reach a reasonable relationship between cost and effect, measured in improved health and raised quality of life”. This wording gives room for individual considerations. However, it does not become any easier for the people working in health care when the committee adds: “any balancing between cost and effect ought to be done after the patient, according to the Swedish Health Care Act, has been informed of the condition of his or her health and the treatment options that are available”.

This can lead to a conflict between the health care staff as the patient’s representatives and the economic reality.

The application of this prioritisation principle is made more difficult because there are often no analyses of cost-effectiveness, especially in the field of nursing care/methods [this is evident from an earlier section in this report]. The fact that there are no formal health-economics analyses does not, however, mean that one has to refrain from making a rough assessment of the cost-effectiveness. Indeed, in certain cases, nursing care involves a requirement for high-tech, expensive interventions, but for most nursing care, the time spent and level of skills of the person providing the care can be sufficient as a rough measure of the resources used and of the cost involved.

One obvious problem is that methods with the best documentation as regards effect and cost can easily be prioritised ahead of methods that lack good scientific documentation. To register a new drug requires, as a rule, two major clinical trials – there the effects have by definition already been documented. Surgical interventions are often less well scientifically documented, but the scientific base for this is rapidly improving. It is more worrying with methods for nursing care and rehabilitation. There is rarely any basic reliable scientific data from controlled studies. This means that nursing care and rehabilitation risk ending up in the reject class when priorities are set strictly on the basis of the cost-effectiveness principle. This is one of many reasons why more research into nursing care is required.

# Footnotes

- <sup>1</sup> Anell & Hjortsberg, 2001
- <sup>2</sup> Öppna prioriteringar i hälso- och sjukvård. Slutrapport från Svenska Läkaresällskapets prioriteringskommitté 2004
- <sup>3</sup> Norberg, Engström, Nilsson 1994
- <sup>4</sup> Lövgren, Engström, Norberg 1996
- <sup>5</sup> Socialstyrelsens allmänna råd, SoSFS 1993:17
- <sup>6</sup> Willman m fl 2003
- <sup>7</sup> Sundin 2001
- <sup>8</sup> Axelsson 1998
- <sup>9</sup> Jacobsson 2000
- <sup>10</sup> Westergren 2001
- <sup>11</sup> Widar 2003
- <sup>12</sup> Omvårdnad som akademiskt ämne, SSF 2002
- <sup>13</sup> Kirkewold 2003
- <sup>14a</sup> Benz 2000
- <sup>14b</sup> Gant & Davis 1997
- <sup>15</sup> Nydevik & Eller 1994
- <sup>16</sup> Low, Payne & Roderick 1999
- <sup>17</sup> Nilsson, Axelsson, Gustavsson, Lundman & Norberg 2000
- <sup>18</sup> Secrest 2000
- <sup>19</sup> van der Smagt, Djuijnstee, Hamers & Huijer Abu-Saad 2000
- <sup>20</sup> Socialstyrelsen: Att drabbas av stroke. Hur ser situationen ut två år efter insjuknandet? Äldreuppdraget 2000:13
- <sup>21</sup> Hulter Åsberg K, Johansson L. Två år med stroke ur ett anhörigperspektiv. Socmed tidskrift 2002:2:146-152
- <sup>22</sup> SOU 1993:93, Vårdens svåra val. Rapport från utredningen om prioriteringar inom hälso- och sjukvården, Stockholm 1993
- <sup>23</sup> SOU 1995:5 Vårdens svåra val. Slutbetänkande av prioriteringsutredningen Stockholm 1995
- <sup>24</sup> NOU 1987:23
- <sup>25</sup> NOU 1997:18
- <sup>25</sup> Det goda valet – prioritering i omvårdnad, SSF & Spri 1998