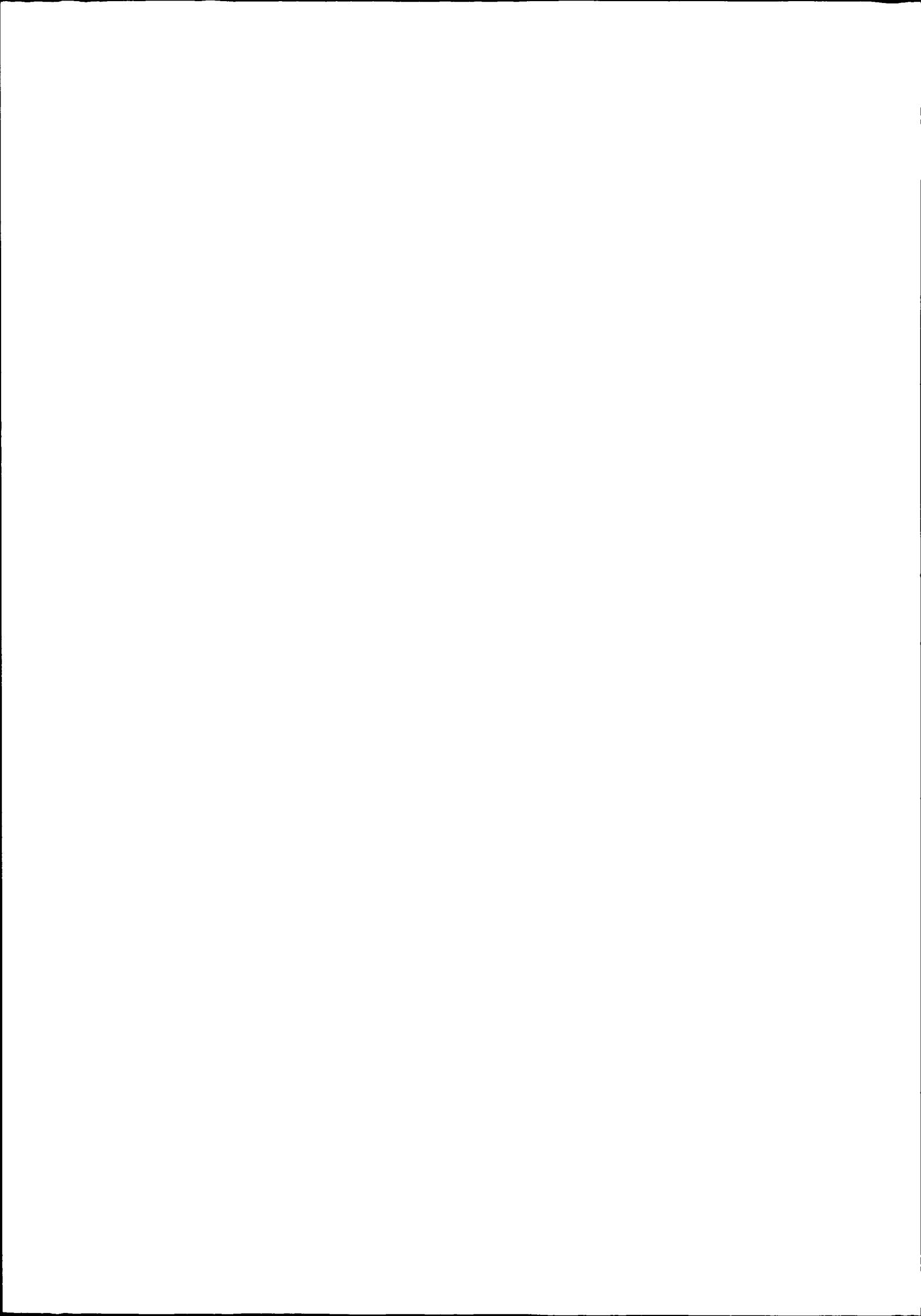


PATIENTS IN A VEGETATIVE STATE

DIAGNOSIS, PREVALENCE AND LONG-TERM CARE
IN DUTCH NURSING HOMES

JAN LAVRIJSEN





Patients in a vegetative state

Diagnosis, prevalence and long-term care in Dutch nursing homes

Jan Lavrijsen

It's too late to stop now

Van Morrison, 1974

The research presented in this thesis was performed by a researcher of the care organisation 'De Zorgboog' in Bakel in co-operation with the Department of Nursing Home Medicine of the Radboud University Nijmegen Medical Centre, the Netherlands. This thesis has been prepared by the Department of Nursing Home Medicine and within the programme of the Nijmegen Centre for Evidence Based Practice (NCEBP), one of the approved research institutes of the Radboud University Nijmegen and the Netherlands School of Primary Care Research (CaRe), acknowledged by the Royal Dutch Academy of Sciences (KNAW). The study was financed by De Zorgboog, which participates in the University Network of Nursing Homes Nijmegen (UVNN).

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Patients in a vegetative state

Diagnosis, prevalence and long-term care in Dutch nursing homes

een wetenschappelijke proeve op het gebied
van de Medische Wetenschappen

Proefschrift

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Contents

1.	Introduction	7
2.	Medical treatment of patients in a vegetative state: a contribution of nursing home medicine	17
3.	Events and decision-making in the long-term care of Dutch nursing home patients in a vegetative state	27
4.	Filamentary keratitis as a chronic problem in the long-term care of patients in a vegetative state	45
5.	Diagnosis of vegetative state as a basis for medical treatment on the borderline between life and death	53
6.	Prevalence and characteristics of patients in a vegetative state in Dutch nursing homes.....	65
7.	Allowing a patient in a vegetative state to die in hospital under the direction of a nursing home physician.....	81
8.	Main conclusions and general discussion.....	91
	Summary.....	113
	Samenvatting	123
	List of publications	133
	Dankwoord	137
	Curriculum vitae	142

De cover symboliseert de liefdevolle verzorging voor patiënten in een vegetatieve toestand
de vraag of iets daarvan doordringt
en het uiteindelijk in liefde kunnen loslaten

The cover symbolises the tender loving care for patients in a vegetative state
the question being whether there is some awareness of this
and ultimately being able to lovingly let go

De MRI-scan is gemaakt door dr. Miranda van Turenout

F C Donders Centre for Cognitive Neuroimaging, Radboud University Nijmegen

Voor mijn ouders

Chapter 1

Introduction

To be or not to be, that is the question

Zijn of niet zijn; daar gaat het om

William Shakespeare

Introduction

Prologue

When I first started working as a physician in a nursing home halfway through the eighties, I was confronted with a special category of patients. Unlike most of the nursing home patients, they were young, often younger than I was. They had their eyes open and they showed a sleep-wake cycle, but there were no signs of consciousness. It was therefore not possible to make contact with these patients. An initial, much quoted, publication of Jennett in 1972 described this state as 'awake but not aware' ¹. It was then that the term 'vegetative state' was introduced for the first time, yet the term (chronic) coma or coma vigil still remained widely used in the Netherlands for many years to come ².

The case history of these patients was impressive, as each one of them had been at the wrong place at a brief, dramatic moment during their lives, often hit by a car in traffic. They were lying in single rooms at the end of a corridor and seldom left their rooms except for a shower. Their appearance often no longer resembled photographs from the past. They received extremely intensive care, in which various paramedics were involved. The manner in which the nursing staff cared for these patients for years won much respect in a situation in which any prospect of improvement was lacking, there was never a response from the patient and the physical care was hindered by spasms and contractures. The families paid visits on a regular basis, even after years and years, and their sorrow was beyond description. We were all moved by the feelings of powerlessness and hopelessness that we shared. These feelings were strengthened whenever we looked back on the stay of many years after one of these young patients had died. All sorts of questions concerning the point of providing treatment and care then surfaced, such as: what did we contribute to the well-being of this patient, was it dignified, how long should we continue the treatment, should we do everything possible in that respect and for whom we treated the patient?

After all, the technical developments in modern medicine had made it possible during the past decades to avert the patient's death in the acute phase of the coma and to keep the patient alive with artificial nutrition and hydration for a long time after that. These patients would have died without the modern facilities of intensive care wards in hospitals. The latter is still the case in those countries where one cannot dispose of facilities of this kind. As it is, the issues relating to the vegetative state confront us with the other side of the successes of curative medicine. The research that is described in this thesis can therefore not be detached

from this context and from a reflection upon medical proceedings Nursing home physicians know the other side of successful medicine, precisely because they are referred many patients who are considered to be 'no longer treatable' in a curative sense The latter particularly applies to the category of patients in a vegetative state, a fate that is sometimes described as 'worse than death' ^{3 4}

Little was known about this group of patients during the first years of my career as a nursing home physician, let alone anything about caring for them in the long term The problems seemed to be hidden away in out-of-the-way rooms Sometimes the dramatic nature of actual cases elsewhere would seep through via the media, the situation surrounding the fate of Ineke Stinissen drew international attention in this respect She came to be in a vegetative state following an incident during a Caesarean section Her husband tried for years and years to end her hopeless situation by legal means In a television broadcast, he explicitly placed the responsibility for a solution with the medical world, as it was within this context that the problem had originated in his opinion That television broadcast, entitled '*To be or not to be*', was an important incentive for me to focus attention on the fate of these patients and their families An album cover of Van Morrison with the title '*It's too late to stop now*' was visible in the background during the interview with Stinissen According to publicity at that time, the dilemma seemed mainly to consist of *either* continuing the treatment of these patients, *or* actively terminating life It could not yet be anticipated at that time that the scenario's as described in chapter 2 of this thesis could later also contribute to creating opportunities for a middle course elsewhere withdrawing futile medical treatment

My first experience with the withdrawal of artificial nutrition and hydration in 1989 constituted a 'landmark case' of sorts in that respect and a definitive incentive to make these positive experiences available to others Particularly in this case, I was confronted with the elementary question in medical science what can I contribute to the well-being of the patient in this situation and in my capacity of physician? Here, the dilemma between being responsible for continuing a form of treatment that is experienced more and more as futile, with all its consequences, and assuming the responsibility for not allowing that situation to continue, became tersely apparent Due to complications relating to the tube feeding, we were forced in this case to evaluate the continuation of the treatment as a whole, including a critical consideration of the role of artificial nutrition and hydration Purely professional arguments served as a guideline in that respect, mainly because there was not any jurisprudence at that time concerning the discontinuation of artificial nutrition and hydration with respect to this category of patients

In an article in 1985, however, Leenen † (professor in Social Medicine and Health Law) although cautiously as yet, had opened up the possibilities from a legal point of view to regard and assess the artificial feeding of patients in a vegetative state as medical treatment⁵ In order to avoid any misunderstandings, he emphasised the distinction between three situations 1) nutrition and hydration as a general human need, 2) nutrition and hydration as part of the normal nursing and care, and 3) nutrition and hydration as a form of medical treatment His substantiated conclusion to include the artificial nutrition and hydration of patients in a vegetative state in the third category was significant at that time so as to have physicians (once again) assume the responsibility for decisions regarding whether or not it should be continued For us, the first description of a positive experience with this responsibility, with a subsequent judicial review, therefore marked a new step towards looking for solutions regarding these issues

This new step coincided with an important milestone in the development of the field 'nursing home medicine' in 1989 the start of the vocational training program for nursing home physicians⁶ Even before this new specialty came into existence in 1990 and my intensive involvement in the education in this field, I learned that nursing home physicians in particular are challenged to creatively look for individual possibilities behind the often serious problems, impossibilities and limitations There seems to be no other field in which that skill is more essential than precisely when dealing with patients in a vegetative state, as it constitutes one huge exercise in dealing with powerlessness Exchanging practical experiences and providing education on patients in a vegetative state were important ways in the 90s in which to do something with that sense of powerlessness

It is exactly that powerlessness and the need to develop specific knowledge of the long-term issues that ultimately led to this thesis It is the result of a passionate quest for new knowledge and solutions in order to lighten and to prevent as much as possible the fate of these patients and their families This quest therefore took place against the background of the rapidly developing field of curative medicine, as well as within the context of the development of a new medical specialisation, the mission of which is found in the care of vulnerable people for whom recovery is no longer possible The heuristic approach, finding one's way by exploring possibilities, was characteristic of the early stages in that field This still applies to research pertaining to nursing home medicine, as this young specialty, in its existence of 15 years, is building up a research tradition The research in this thesis must therefore be considered in that context, in which the initially heuristic approach in a

unexplored territory will ultimately shift to an empirical and analytical approach, partly on the basis of intervention studies and Evidence Based Medicine and Practice.

The right lines came together at the right moment at the start of this study in 2000. On the day that one of the patients in this study suddenly died, it was concluded that this was the right subject, with the right people and within the infrastructure that had meanwhile been put together, for research both at the nursing homes of 'De Zorgboog' in Bakel, as well as at the Department of Nursing Home Medicine of the Radboud University Nijmegen Medical Centre. The start had already been made in the past and publicity and discussions with people with various backgrounds and views were not avoided upon concertedly exploring the possibilities and limitations of medicine. From the very first publication to the present day, these discussions also inspired me to continue to take a critical look at my own view and to feed the experiences in practice and this field of education with even more new knowledge based on research.

Research questions and goals

The questions pertaining to this study are:

- How, by whom and at which moment in time, can the *diagnosis* vegetative state be made as accurate as possible?
- What is the *prevalence* in Dutch nursing homes with respect to a vegetative state following acute brain damage and what are the characteristics of this population?
- What is the *long-term course and care* for patients who have been admitted to a nursing home in a vegetative state following acute brain damage and who are not expected to recover anymore?

The *general goal* of this study is to contribute to clarity regarding the course of the vegetative state in the long term. And with that, the study also aims to create a realistic picture of the practice of nursing home medicine.

The following *specific goals* can be named as well: describing a population of patients in a nursing home who are in a vegetative state following acute brain damage and who are not expected to recover anymore, and the medical treatment that has been provided in that respect in the nursing home; determining the prevalence in Dutch nursing homes with respect to a vegetative state following acute brain damage, making a contribution to the quality of the medical treatment that is provided in nursing homes in the care of vegetative patients and

their families, and developing medical education with respect to vegetative patients in nursing homes

And so the study can lay the foundation for recommendations concerning treatment in actual practice and for further studies regarding an identifiable group of patients. By interpreting the data, we hope to also find an answer to the question of how a hopeless vegetative state could be prevented.

Outline of this thesis

Chapter 2 includes the first publication as referred to in the introduction regarding the discontinuation of the treatment, including artificial nutrition and hydration, of a female patient in a vegetative state. This clinical lesson describes the contribution of nursing home medicine to a broad public debate that arose, particularly in the early 90s, regarding the dilemmas in the long-term care of these patients when there is no longer hope that they will regain consciousness. In a time in which there was not, as yet, any jurisprudence regarding the legitimacy of withdrawing artificial nutrition and hydration as a form of medical treatment, it was the first time that the decision-making process and the considerations in that respect were publicly described. In order to provide as much insight as possible into these decision-making processes against the background of the clinical course, it was decided to opt for a descriptive set-up in the form of a clinical lesson. The experience and the subsequent positive reactions gave cause to conduct further studies into the issues in the long-term care of patients in a similar state.

This part of the study is described in *chapter 3* in the form of a qualitative, descriptive study of events and decision-making processes regarding the long-term care of patients in a vegetative state in Dutch nursing homes. Here, the long-term course of events is described for five nursing home patients of whom, after being in a vegetative state for the duration of a year, it is no longer expected that they will regain consciousness. In addition to a case description, an integrated overview is also provided for each patient regarding co-morbidity, multi-disciplinary care and treatment, as well as the main lines concerning the decision-making process with respect to medical proceedings. As previously mentioned, this part of the study took place against the background of the development of the field of nursing home medicine during a period of 25 years. Thanks to the chronological order of the case histories that were presented during that period, it was possible to apply what we learned from each

individual case in each subsequent case. This part of the study aims at filling the gap in the literature that was found with respect to long-term follow-up studies of patients in a vegetative state.^{7 8}

Chapter 4 describes an ophthalmic complication that we observed in two of the five patients during the retrospective study as described in chapter 3. Before then, the phenomenon of a filamentary keratitis was not known in relation to an accurately described, prolonged vegetative state. We can only speculate on how this disorder develops. The descriptive case study also portrays a therapeutic intervention that has been successful to date based on changed speculations about the relation between filamentary keratitis and vegetative state.

Chapter 5 describes a diagnostic concept for the vegetative state. After all, it had become clear during the literature study that – where it concerns determining something that is lacking, namely consciousness – there are not many international, standardised guidelines that can be used following the acute phase. It is precisely during this phase, when the eyes are open and automatic, reflex movements may occur, that misinterpretations are likely and that there is a need for refined, diagnostic methods so that subtle changes are also included. This certainly applies to the nursing home situation as well, in which these changes are mainly reported by the family or the nursing staff, with all its impact. The need for a reliable, diagnostic method is emphasised even more by the fact that, by legalising the discontinuation of forms of treatment with respect to patients in a vegetative state, the main point of the decision then shifts to making the correct diagnosis. In order to meet this need, chapter 5 describes the univocal use of terminology and provides an answer to the question how the diagnosis – by whom, when and on which grounds – can be made. This helping hand is the result of literature research and a debate on the subjects of discussion from that literature during an expert meeting that we organised. This publication laid the foundation, in terms of content, for the study concerning prevalence as described in chapter 6 and for a practical application as described in chapter 7.

Chapter 6 describes the empirical research into the prevalence of a vegetative state following acute brain damage in September 2003 in Dutch nursing homes. In addition, an assessment is made of the main characteristics of the population as found. As we also wished to know whether or not the prevalence as found could be associated with a systematic discontinuation of treatment, including artificial nutrition and hydration, in previous years, the

study also included inquiries after the number of patients in a vegetative state to receive treatment as of the year 2000. We requested data on the moments in time when the treatment was terminated with respect to the patients in this population. This part of the study aims to provide a realistic picture of the quantitative scope of the long-term problems regarding the vegetative state in the Netherlands. By making an assessment of the population, we can also lay the foundation for subsequent research.

Chapter 7 provides a description of a medical intervention under direction of a nursing home physician in an early stage of the vegetative state outside the nursing home. The diagnostic concept as described in chapter 5 is applied in this case and the nursing home physician takes over the responsibility for the medical treatment from the medical specialist at the hospital. This descriptive case study describes the multi-disciplinary method of working of the nursing home physician and the possibilities of preventing a permanent, hopeless, vegetative state at an early stage of the treatment from that approach. Learning aspects from previous experience and research are applied in this respect in a transmural setting of nursing home medicine, a transfer unit in a hospital.

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Chapter 2

Medical treatment of patients in a vegetative state: a contribution of nursing home medicine

Published as JCM Lavrijsen, JSG van den Bosch Medisch handelen bij patienten in een chronisch coma een bijdrage uit de verpleeghuisgeneeskunde *Ned Tydschr Geneeskd* 1990,134 1529-32

However, there does appear to be a point when a reasonable person would decide 'enough is enough'. Unfortunately, it is difficult to be that person

Er lijkt echter wel een moment te zijn waarop een redelijk persoon tot het besluit zou komen 'genoeg is genoeg'. Helaas is het moeilijk om die persoon te zijn.

Bontke CF, Dolan JM, Ivanhoe CB. *J Head Trauma Rehabil* 1994

Medical treatment for patients in a vegetative state: a contribution of nursing home medicine

Ladies and Gentlemen,

In 1985, in this journal, Minderhoud and Braakman described a number of patients who ended in a vegetative state after brain damage ¹ In 1972, it had already been suggested in *The Lancet* to call this condition 'persistent vegetative state' (PVS), as this definition describes the syndrome best ² From then on, this term was used more and more in the literature ^{3 15}

As a result of brain damage, PVS patients no longer show any of the higher brain functions, but activities of the isolated brain stem can still be observed, such as a sleep-wake rhythm (opening of the eyes), cough reflex, teeth grinding, lip smacking and compulsive crying The patients breathe independently, but need to be fed artificially by a nasogastric tube or by a gastrostoma There are no signs of purposeful behaviour or interaction with the environment, the patients are 'awake but not aware' PVS may occur after skull trauma, massive bleeding in both hemispheres or other types of acute brain damage, for example, due to hypoxia or hypoglycaemia In the acute phase of these types of damage, the patient is comatose the eyes are closed, there is no response to stimuli, and taking over vital functions such as breathing may be necessary As the cough reflex is lacking, the risk of aspiration pneumonia is considerable

In this condition the patient is therefore entirely dependent on complex medical technology Those who survive the comatose phase as a result of this care may recover In accordance with the much used Glasgow Outcome Scale, the degrees of recovery may be described as follows good recovery, moderate disability, severe disability with full dependency, and PVS ³

In the case of PVS the above-mentioned brain stem activities develop after some time Consequently, with the provision of care and enteral nutrition, the patient may survive for a long time

After one year, more than 1% of the patients with trauma-related brain damage who had been comatose for more than 6 hours proved to be in PVS ¹⁶ The prognosis is very bleak already after 1 month of PVS, no one over 40 will ever become independent again, after 3 months, this goes for all age categories ¹⁶ Recovery after 1 year is very rare In the literature

there are only a few cases in which the patients had still regained consciousness. They were severely disabled and fully dependent on others for their daily support^{4 7 10}

If treatment is suggested, PVS patients are usually taken to a nursing home a few months after the acute phase. Therefore, nursing home physicians have acquired quite some expertise in the care for and treatment of this category of patients. Years of experience with multiple patients in our nursing homes has led to the development of an approach in which prevention of long-term PVS has become the main point of departure. The following case was of critical importance in this development.

After a car crash in 1983, patient A, a 43-year old woman, was hospitalised with jaw fractures, soft tissue damage, and a contusio cerebri. Computerised tomography showed no visible abnormalities of the skull. Twelve days after admission the patient had a hypovolemic shock resulting in asystole and apnoea, due to a ruptured spleen, as later proved. After reanimation and a splenectomy, the patient did not regain consciousness. The patient was started on nasogastric feeding, and a treacheostoma was made for bronchial toilet. After 9 weeks, she was transferred to our nursing home as a patient in PVS.

As it was not sure that the patient would never regain consciousness, the nursing home physician pursued a curative policy in the first few months. In addition to normal care, nursing was particularly focused on tube feeding, prevention of decubitus, and oral hygiene. Physiotherapy was provided to prevent contractures. As the cough reflex was still intact, the patient was well able to cough up sputum. The trachea cannula was therefore removed without any problems after 2 months, whereupon the stoma gradually closed. Over the first 6 months, there were no changes in the state of her unconsciousness. The physician and the family had by now given up hope that she would ever recover. After consulting the GP and the family, the nursing home physician and his staff developed a policy of abstinence in which non-treatment of life-threatening complications was an option. In the years that followed, such complications did not occur. However, ever since she had been admitted to the nursing home, she had had recurrent bouts of compulsive crying and restlessness, sometimes in response to sound, sometimes during physiotherapy, or when the tubes were changed. To combat these symptoms, various medicines were tried, until finally diazepam was opted for.

Five years after admission, there were increasing problems with tube feeding. The tube got clogged, needed to be changed more regularly, and was vomited out a number of times. After consulting the family, the treating physician at the time made arrangements for a gastrostomy. Because another physician took over and because of family circumstances, this

surgery was postponed. In the early part of 1989, six years after admission, the patient developed aspiration pneumonia after she had vomited out the tube. The GP and the family were again consulted, but now by the new physician, and in line with the abstinence-from-treatment policy, it was decided to abstain from treatment. The patient did not die and the situation stabilised spontaneously. After a quiet phase, the problems with the tube became more serious and more frequent: the tube was vomited out several times a week, sometimes together with blood, under the clinical picture of serious dyspnoea with large amounts of sputum that could not be coughed up. There was a rapidly increasing risk of suffocation. Because of this dyspnoea and restlessness, insertion of the tube caused problems and often needed to be postponed. Only a few nurses could still do it properly. The dyspnoea was so physically stressful that intervention was deemed necessary. The physician was aware of the dilemma he was facing: he wanted to give the patient the opportunity to die, but he did not consider the circumstances acceptable. He discussed this dilemma with a team of six nursing home physicians, who agreed with him as to the treatment of the dyspnoea. The treatment with tube feeding - which was becoming more harmful than helpful to the patient - was also discussed at this meeting. Gastrostomy was discussed against the background of the patient's health situation at the time and what it would be like in the future.¹⁷ It became clear that this intervention might solve the tube feeding problems in the short term, but would not contribute to the patient's well-being in the long term. Moreover, the family had not given their consent. Under these circumstances the doctors decided not to operate, such on the basis of non-interference, as this intervention did not serve the interests of the patient, and also because they did not have the consent of the patient in question.^{18 19}

As it was also clear to everyone that the existing physically stressful situation should not be maintained, the whole treatment was reconsidered. This reconsideration, in which continuation of treatment was eventually deemed futile, led to the conclusion that not inserting the tube again, which would lead to the death of the patient, was an acceptable consequence in this situation. There was one condition, however, namely that this would be based on the conviction that the patient was not going to experience any suffering as a result of the withdrawal of artificial nutrition and hydration. The doctors were convinced of this because of their extensive experience with nursing home patients who stop drinking and eating in the terminal phase, and then die quietly in a uremic coma 1-2 weeks later. The outcome of the reconsideration was discussed with the nurses and with the family, who supported the team of doctors in their intention to cease treatment as they were convinced that this was in agreement with the personal values and supposed wish of the patient.

As the patient would die as a result of this decision, the need for a test against ethical criteria was felt. When requested to make such a test, Prof. Sporken, Eminentus Professor of Medical Ethics at Maastricht, came to the conclusion that there were sufficient ethical grounds to justify such a decision. After this final test, the physician decided to cease the treatment of this patient, who had remained 6.5 years in a constant PVS without any hope of recovery. All those involved were subsequently thoroughly informed, especially the nursing staff. A chemist and an internist were consulted in connection with controlling compulsive crying in the final phase. After all, in this phase, the tube could no longer be used to administer the diazepam solution, and the people present might erroneously associate compulsive crying with suffering. A single depot injection of 50 mg haloperidoldecanoate was opted for. Besides the wish to control the compulsive crying, there were also other arguments that played a part in this: a single injection with a repository preparation does not lead to more unnecessary acts in a situation in which medical treatment has been ceased.

The very next time that the patient's dyspnoea once again required the removal of the tube, the physician decided to effect the decision not to reinsert the tube. From that moment on, there was finally real peace. The diazepam solution was now replaced by the haloperidol injection. All the family had come to say goodbye to the patient, also those people who had not seen her for a long time. Finally, the unfinished mourning process that had lasted so many years was to come to an end. One week after the tube feeding had been stopped, the patient died peacefully. Neither the family, nurses nor the physician saw any signs of suffering in this phase. On the contrary, the family experienced the final phase as meaningful and humane.

Discussion

This dying process, experienced by all the people involved as humane, contrasts strongly with the shocking picture that some of our colleagues like to paint in the media. We deplore this, because truthful representation plays an essential part in the decision-making process and information to the people involved.

In nursing home medicine, we frequently see normal, peaceful dying processes, in which patients do no longer eat or drink anything. Psychogeriatric patients who resolutely refuse all food and drink also die peacefully. Moreover, on medical grounds, we do not assume that PVS patients experience thirst, hunger or pain. Such experiences require an integrated functioning of the brain stem and the cerebral cortex, which is not the case in PVS patients.^{8 11} Data available from post-mortem research on PVS patients point to such bilateral damage to both hemispheres that experience of these sensations cannot be assumed present.⁹ The same

goes for the degree of reduction in the glucose metabolism of the cortex, as seen in positron emission tomographies.⁹ Electroencephalograms are not relevant in this context: as regards PVS they show large variance, and the variations do not agree with the clinical picture.^{6,8} On the basis of these available data, we cannot find any medical argument to resort to actively ending the lives of PVS patients. Furthermore, there is the objection of principle that the patient him or herself has not made the required request. Our approach to the dying process in PVS patients is basically not different from how we approach this process in other patients.

Experience with multiple PVS patients has shown that non-treatment of intercurrent infections does not automatically lead to the death of the patient. Good nursing, good nutritional state, an intact cough reflex, and young age may be factors that either prevent death from complications or postpone it for a long time. The longest term of survival recorded was more than 37 years.¹¹

If it is a question of waiting for complications, it is rather paradoxical to consider tube feeding useful on medical grounds and abstain from other treatment on those very same medical grounds.¹² Instead of asking whether it is justified to cease treatment, one should ask whether it is justified to continue treatment. The complications in this case were eventually the reason for us to pose this question. For the physician, there were sufficient arguments to consider continuation of treatment futile. There was no longer a reasonable relation between the medical means and the intended goal, which Leenen considers one of the criteria for withdrawing a medically futile treatment.²⁰ The medical nature of this type of tube feeding has already been confirmed in several publications,^{8-10 12-14 20 21} and has recently also been recorded in Dutch case law.²²⁻²⁵

Although withdrawal of treatment may be less emotionally fraught when complications occur, the physician will also have to reconsider the indication of tube feeding in cases of uncomplicated PVS. This indication has after all changed. The indication at the beginning of treatment, i.e. bridging a period of time until possible recovery from coma, is not applicable in cases of PVS. The sole indication is then to keep the patient alive without making any demonstrable positive contribution to his/her well-being. In this new context, medical doctors will have to evaluate from a medical professional perspective whether or not a medical procedure contributes to the well-being of the patient. This involves a direct assessment of the question of whether their own medical acts are useful or not. This difficult judgment will be, and should continue to be, the subject of discussion. The medical doctor who evaluates his own actions carefully will submit this judgment to his colleagues, and will discuss it with the patient's family and with representatives of the disciplines involved in the treatment. Besides

medical information on diagnosis and prognosis, active family guidance from the time of admission is required to let the family gradually 'grow' in a decision-making process of this kind.

When there is no longer any hope of recovery, and the family has come to terms with the reality of the patient's situation, a doctor's careful decision to withdraw treatment may be acceptable.^{9 10 12 15 19} We discussed and tested this step in consultations with our colleagues. These consultations also led us to develop our own points of view on the prevention of long-term PVS. In this we did not focus on withdrawal of certain parts of the medical treatment, but on evaluation of the whole treatment. By a more active approach based on principles we want to prevent ad hoc solutions in crisis situations. In this respect it is advisable to use guidelines for due care that have been formulated in advance, and in which certainty about diagnosis and prognosis, the (supposed) wishes of the patient and the family, and the times of assessment are basic, crucial factors. The international 'Appleton consensus' gave the initial impetus to further development of these guidelines.¹⁵

Ladies and Gentlemen, anyone who is alert at points at which decisions must be made in the course of PVS and regards treatment as a process that needs to be evaluated on a regular basis, may come to a well considered decision with regard to preventing chronic PVS. In this process, intensive family guidance is an essential condition. If a physician eventually decides to abstain from treatment, the withdrawal of artificial nutrition and hydration will not lead to a degrading situation, but to a humane demise of the patient. On the basis of our experiences we therefore conclude that there is no argument whatsoever that would justify active, unrequested ending of life in the case of PVS patients. On the basis of specific experiences with patients in this situation, nursing home physicians may contribute to the current debate on this problem by providing insight into the basic principles and careful decision-making. We sincerely hope this lecture will have served this noble purpose.

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Chapter 3

Events and decision-making in the long-term care of Dutch nursing home patients in a vegetative state

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It is one of the most tragic things to witness, how sudden and inescapably the conscious mind disappears from someone who lives on, and it is one of the most painful things to have to explain to the family.

Het is een van de treurigste dingen om te zien, hoe plotseling en onontkoombaar de bewuste geest verdwijnt uit iemand die in leven blijft, en het is een van de pijnlijkste dingen om aan de familie uit te moeten leggen.

Uit Antonio R Damasio Ik voel dus ik ben Hoe gevoel en lichaam ons bewustzijn vormen
(Oorspronkelijke titel The feeling of what happens) 2001, *wereldbibliotheek Amsterdam*

Events and decision-making in the long-term care of Dutch nursing home patients in a vegetative state

ABSTRACT

Objective

To clarify characteristics of long-term care and treatment of patients in a vegetative state

Design

Qualitative, descriptive study in a Dutch nursing home

Methods

Review of clinical records of patients in a vegetative state after acute brain damage between 1978-2002

Results

Five patients received intensive care of a multi-disciplinary team and showed considerable co-morbidity. There was no standard scenario for end-of-life decisions. Physicians play a more proactive role by evaluating the total medical treatment instead of withholding therapy in case of incidental complications. The families' attitude is a crucial factor in their ultimate decision.

Conclusions

There is no standard solution to alleviate the fate of patients in a vegetative state and their families. Withdrawing all medical treatment, including artificial nutrition and hydration, can be an acceptable scenario for letting the patient die. More research is needed to identify the factors that contribute to acceptance of the physician's decision by the family.

Introduction

Patients in a vegetative state have survived an acute brain accident, but did not regain consciousness. In contrast to coma patients, patients in a vegetative state open their eyes and show a sleep-wake cycle, they are 'awake, but not aware'.^{1 2} Reviews of diagnoses and prognoses show that recovery after one year is highly unlikely.^{3 4} Questions about the futility of continuing medical treatment after that period have bothered caregivers, family, and society. Unfortunately, long-term follow-up studies on the clinical course and decision-making after one year are lacking.^{4 6}

Long-term care is mainly based on learning by experience. There is, however, much disagreement about which treatment decisions are appropriate and which factors should influence decision-making.⁷

This study analyses the long-term care in the total caseload of patients who spent more than one year in a vegetative state after acute brain damage in a Dutch nursing home. The aim is to determine the key factors in the long-term course, the characteristics of treatment and care and appropriate scenarios for preventing a long-term vegetative state. This study will try to answer the question of if withdrawing artificial nutrition and hydration (ANH) can be appropriate when no recovery is expected. Recent news reports made clear that this is still a controversial topic.^{8 9}

Methods

A retrospective, descriptive review was conducted of the clinical records on all the patients in a vegetative state who were admitted to one of the four nursing homes - that currently form the Zorgboog-foundation - between 1978-2002. These records comprise the medical, paramedical and nursing records. All patients met the following criteria:

- a diagnosis of vegetative state³ or coma vigil after an acute traumatic or non-traumatic brain accident,
- confirmation of the diagnosis by a neurologist or nursing home physician,
- a Glasgow Coma Scale score of E4-M4-V2 maximum¹⁰ and/or observations described in accordance with the criteria of the Multi-Society Task Force on Persistent Vegetative State³
- a vegetative state lasting more than one year

From the records, the following data were derived: patient characteristics, co-morbidity and medical treatment, consultations, decision-making, and scenarios of dying. In all cases, the

first author (JL) was involved in the diagnosis, management, and review of case notes. The second author (HB) was involved in the evaluation of each case as medical director. Learning points were formulated after each case and then taken into account in the next cases.

Results

Between 1978-2002, nine patients were admitted with the above-mentioned diagnosis. Three of them regained consciousness within six months, of whom two were discharged to a psychiatric clinic and one to a rehabilitation centre. Another patient, who nowadays would have met the criteria of Minimally Conscious State,¹¹ was discharged to an institution for mentally disabled people.

Five patients were identified as being in a vegetative state for more than one year. Table 1 shows the main characteristics of these patients.

The case reports in the Appendix provide a qualitative insight into the long-term course and the different medical end-of-life scenarios. In addition to the individual data, we will present general patterns in nursing care, medical treatment, clinical course, and decision-making.

Patterns of similarity

None of the patients studied regained consciousness. Long-term care was provided by a multi-disciplinary team consisting of several nurses, a physiotherapist, speech therapist, occupational therapist, dietician, pastor, social worker, and psychologist, under the leadership of a nursing home physician. Daily nursing care was intensive: washing, changing incontinence materials, supplying ANH six-eight times a day, frequent turning to prevent bedsores, fixing splints, cleaning the tracheal tube, providing mouth care, supplying laxatives and other medicines and regular changing of the urinary catheter and nasogastric feeding tube. Later on, feeding pumps and PEG (Percutaneous Endoscopic Gastrostomy) tubes facilitated the care and diminished the problems.

All patients showed considerable co-morbidity, as seen in Table 1. The medical problems included chronic constipation, spasticity with contractures, mouth and dental problems and regular infections of airways, urinary tract and skin. Severe infections were not always lethal in this young, well-fed population. Despite immobility, bedsores occurred only incidentally. Remarkable findings were filamentary keratitis in patients 4 and 5 and spontaneous recovery of hormonal deficiencies after more than one year in cases 2 and 5.

Chronic medicines were administered, especially laxatives, and various medical specialists were consulted (Table 1).

Table 1: Main characteristics patients and events

N	Age ¹	Sex	Cause and year of beginning	Survival	Medical problems	Nursing problems	Medication	Consultations
1	17	M	Trauma in 1978	11½ years Died of sepsis (not treated)	Temperature peaks Weight loss Eye/ear infections Chronic constipation Caries, broken teeth Extreme spasticity Respiratory infections Haemoptysis Chr. urinary tr. infections Urinary stones, obstruction Haematuria Fistula, abscess Repeated skin infections Bedsore in terminal phase	Contractures Mouth care Teeth grinding Tube problems Catheter problems Skin infections	Antibiotics (11 courses) Laxatives (chronic) Muscle relaxants (chronic) Antacids Anti-inflammatory drugs Antipyretics Anticholinergic agents Antifungal ointments Mucolytics	Urologist (5x) General practitioner(3x) Dermatologist (3x) Neurologist (3x) Surgeon (3x) Orthopaedist (1x) Internist (1x) Colleagues NHP ² (1x)
2	43	F	Trauma with 12 days later anoxia due to bleeding spleen in 1983	6 years and 5 months Died after withdrawal ANH ³	Eye/ear infections Chronic constipation Caries, loose teeth Extreme spasticity Respiratory infections Haemoptysis, dyspnoea Urinary tract infections Incidental bedsore Temporary amenorrhea	Contractures Mouth care Teeth grinding Tube problems Catheter problems Compulsive crying	Antibiotics (4 courses) Laxatives (chronic) Antiemetics Benzodiazepines (chronic) Muscle relaxants Mucolytic agents Neuroleptics	General practitioner(6x) Colleagues (6x) Neurologist (4x) Surgeon (3x) Dentist (2x) Internist (2x) Dental surgeon (1x) Ophthalmologist (1x) Orthopaedist (1x) Pharmacist (1x) Ethicist (1x)
3	44	M	Anoxia after cardiac arrest in 1989	1 year and 3 months Died after withdrawal ANH	Temperature peaks Eye infections Repeated skin infections Chronic constipation Regular vomiting Respiratory infections Urinary tract infections Convulsions	Contractures Fetus position Agitation Mouth care Tube problems Catheter problems Myoclonus	Antibiotics (5 courses) Laxatives (chronic) Antacids Anticoagulants (6 months) Antiemetics Benzodiazepines Muscle relaxants (chronic) Corticosteroid ointments Histamine H ₂ -antagonist Anticholinergic agents	Colleagues NHP (11x) Internist (5x) Pharmacist (5x) Surgeon (3x) General practitioner (2x)

4	15	M	Trauma in 1991	8 years and 4½ months Died after pneumonia (despite treatment)	Skin infections Chronic constipation Keratitis filamentosa Eye/ear infections Moderate spasticity Incidental seizures Respiratory infections Haemoptysis, dyspnoea	Contractures Excessive salivation Frequent administration of medication (eye)	Antibiotics (17 courses) Laxatives (chronic) Anticonvulsants Antifungal ointments Benzodiazepines Mucolytic agents Histamine H ₂ -antagonist Anticholinergic agents Corticosteroid ointments Indifferent eye ointment	Colleagues NPH(3x) Internist (3x) Ophthalmologist (2x) Dermatologist (2x) Neurologist (2x) Surgeon (2x) Dentist (1x)
5	18	M	Trauma in 1987	Still alive after 16 years in a vegetative state	Temperature peaks Pituitary dysfunction: - ADH deficit (until 3 years after accident) - FSH/LH deficit (until 3 years after accident) - Cortisone and MSH-deficit Chronic constipation Seizures Crurus fracture Osteoporosis Keratitis filamentosa Caries, fungal infections Skin infections Incidental bed sore Respiratory infections Urinary tract infections	Contractures Catheter problems Mouth care Excessive salivation Frequent administration of medication (eye)	Antibiotics (52 courses) Laxatives (chronic) Antipyretics Muscle relaxants Anticholinergic agents Antifungal ointments Benzodiazepines Mucolytics Hormonal supplements (cortisol, vasopressin) Corticosteroid ointments Indifferent eye ointment	Ophthalmologist (17x) Internist (9x) Colleagues NPH (7x) General practitioner (6x) Dentist (3x) Neurologist (3x) Surgeon (3x) Orthopaedist (2x) Pharmacist (2x) Urologist (2x)

¹ At the time of the accident

² NHP: Nursing Home Physician

³ ANH: Artificial Nutrition and Hydration

Decision-making as a learning process

None of the patients had made a living will, and the three youngest patients had previously never expressed any wishes as to treatment in this context. As regards the two patients older than 40, their partners' views were mentioned in the medical records. They both assumed that their partner did not want to continue life under such conditions, and they ultimately accepted the medical decision to withdraw ANH.

At the time, the scenario of withholding medical treatment for complications was the only option to end the vegetative state in case 1. Decisions were made in reaction to events, and no structural meetings were planned to discuss treatment policy with family or colleagues. Locum doctors made their own decisions, as was the case in the treatment of life-threatening urine obstruction in case 1. Ultimately, withholding antibiotics for infection did not lead to the expected death, but resulted in a chronic infectious state that turned out to be an inappropriate way to let the patient die.

The learning point was that, instead of only withholding therapy for incidental complications, regular evaluation of the total medical treatment is necessary.

This scenario was applied in case 2, in which the complications caused us to make such an evaluation. Interventions regarded as futile were withheld and the medical treatment including ANH was withdrawn. All the people involved witnessed a quiet and dignified dying process without signs of discomfort. This scenario was seen as appropriate. The family was informed that the decision was entirely the responsibility of the physician and not theirs to make. Several consultations, especially with colleagues and the family's general practitioner, contributed to this decision-making. The case was published in Dutch medical and lay press and brought to the attention of the Public Prosecution Service.¹² After the case was broadcast on television, a preliminary judicial investigation was started. The conclusion was that 'the decision to withdraw ANH was made with due care from a medical and ethical point of view.'¹³ This conclusion confirmed the view that withdrawing ANH can be regarded as withdrawing futile medical treatment. Moreover, this experience led to the insight that an earlier evaluation of the total treatment could possibly prevent a long-term vegetative state.

This approach was taken as a starting point in case 3, which also involved informing the family that the decision to withdraw treatment would entirely be up to the physician. The family accepted this, after they were intensively guided in their coming to terms with the situation and in their grieving process. In this scenario, a long-term vegetative state could be prevented.

Cases 4 and 5, however, showed that this scenario cannot be applied in all situations. The parents of these young patients could not agree to the withholding or withdrawal of medical therapy. In case 4, there was no other option than to wait for a fatal complication, which ultimately occurred 8.5 years after onset of the vegetative state.

In case 5, the proactive approach, numerous family meetings, incidental complications, and consultations and discussions have not led to any other scenario than to continue treatment. The medical record mentions that this happens at the request of the parents who do not want to lose their loved one, despite the fact that the physicians are convinced that continuing medical treatment is futile for the patient.

Discussion

This study shows that the long-term care of these patients is complex and intensive. The fact that no patient regained consciousness after one year in a vegetative state confirms the general conclusion in the literature.⁴ All patients were fully dependent on intensive nursing, medical, and paramedical care and developed considerable co-morbidity, requiring polypharmacy. The course depended on co-morbidity and the physicians' and families' attitudes. There was no standard solution, not even when physicians were convinced that continuing medical treatment was futile.

This is the first time that events and decision-making in the long-term care of vegetative state patients have been described. The results can be of advantage to other caregivers. This study may have a quantitative limitation, but it is recognised that only a small number of patients is available, usually widely dispersed away from academic centres in hospitals, nursing homes or at home.⁵

Comparison with the few other studies of long-term care is impossible, because these include developmental or degenerative disorders.^{14,16} Single case reports have shown similar co-morbidity (constipation, contractures and infections).^{17,20} As far as is known, filamentary keratitis and spontaneous recovery of hormonal deficits have not been documented before in relation to a long-term vegetative state.

As demonstrated, the role of the physicians has changed over time from reacting to complications to a proactive role in which evaluation of the total treatment, including ANH, has become the starting point. Case 2 was a landmark case in that attitude shift, because of the positive experience, positive reactions and judicial confirmation of due care. Since then, this scenario has been applied in other cases in and outside the nursing home. This positive

experience contrasts with an article previously published, in which the author expressed feelings about letting someone 'starve' ²¹

It is essential that the physician makes a state-of-the-art diagnosis of the vegetative state with the help of a multi-disciplinary team ²² Different phases can be distinguished in the medical treatment the acute phase in hospital, the transitional or 'waiting' phase in which there is stabilisation and hope of recovery and the irreversible or permanent phase in which there is no hope left ^{7 23} In each phase, it is important to hold regular team and family meetings and discuss the goals of medical treatment against the background of the diagnosis and changing prognosis ²²

In the Netherlands, it is justifiable to withdraw ANH as medical treatment of patients in a vegetative state as part of a careful decision to withdraw other forms of life-sustaining treatment, when the chance of recovery is negligible ^{23 24} This policy is in line with a broad consensus across many countries that prolonging the survival of patients in a permanent vegetative state brings no benefit to the patient ^{6 25}

It is also essential to emphasize that withdrawing treatment is a medical decision Statements made by the families (Table 2) and the evaluations show that this is a crucial factor in the families' acceptance of the decision In the authors' opinion, the burden of such a decision should be borne by the physician

Table 2: Key statements made at family meetings

Doctor The parents told me that, should they be confronted with a recurrence of the life-threatening urine stoppage, they would probably insist on medical treatment, but if the physicians were to say that treatment is not the most sensible choice, they would understand (case 1)

Doctor The husband explained that he was afraid to decide himself whether or not complications should be treated He requested not to involve him in the decision making concerning the withholding or withdrawal of medical therapy, but only to explain to him what has been decided (case 2)

Doctor I have told her that I think the time has come that I should decide to withdraw artificial nutrition and hydration No one raised any serious objections (case 3)

Parents We recognize that our son would never have wanted this situation to continue like this, who would? With hindsight, it would have been better for him if he had died in hospital We hope that he doesn't realize in which situation he is (case 4)

Parents This is a fate worse than death, but we don't want to lose him (case 5)

Attitudes of families were crucial in the ultimate decisions of physicians. Intensive guidance of the family towards the key decisions in the different stages of a vegetative state is a necessary condition for preventing a permanent vegetative state. Nevertheless, accepting the consequences of the decision to withdraw medical treatment remains difficult, in this study particularly for parents who have found a new balance in the stable phase. In cases 4 and 5, the families told that they could have accepted the death of their son in the acute phase, but they could not agree to the withdrawal of treatment once a new reality in their relation with their child had emerged (Table 2).

The current questions are how long this situation can be justified when no benefit for the patient is assumed and how it can be prevented by making decisions at an earlier stage. These questions are the subject of further investigation, with a focus on adequate timing of interventions and coping of the family. The 'waiting phase', in which the different scenarios are explained to families, can be a crucial period for preventing a permanent vegetative state. Ultimately, the withdrawal of all medical treatment is better accepted when families are informed.

Hopefully, this insight will promote the co-operation of physicians in acute and long-term care in preventing this desperate situation. Co-operate is the least we can do in a situation created by modern curative medicine, which has ultimately only palliative care and compassion to offer to patients in a permanent vegetative state.

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Appendix

Case 1: withholding antibiotics

This patient was admitted to the nursing home in 1978, 2 months after a motor bike accident, and survived for 11.5 years in a vegetative state. At the time, there was little-to-no experience with these patients.

The first day of admission, the family was preparing for his death because of a temperature peak of 40°C. However, the medical situation stabilized spontaneously. After a neurologist had confirmed the permanent character of the vegetative state, the parents lost their hope of recovery after 2 years. They maintained their request for curative treatment of complications, because they could not accept that they would lose their son.

The first 7 years, complications were treated in a curative way at the request of the family. In total nine courses of antibiotics were given, six for airway infections, two for urinary tract infections and one for folliculitis of the skin. Surgical interventions were also made. An urologist removed bladder stones and, later, at the request of the parents and a locum doctor, stones which had caused bilateral ureteric obstruction were removed.

After this, the futility of medical treatment was discussed in the multidisciplinary team, which also consulted the family's GP in this matter.

Seven years after admission, the family was finally willing to accept the physician's decision to withhold curative treatment of complications. This scenario did not lead to the patient's death, but to a state of chronic urinary infection; he survived periods of high fever in which antibiotics were withheld. Four years later, the result was purulent outflow from his penis, bedsores, purulent sputum, fistulas on his scrotum and a suprapubic abscess, which required surgery and antibiotics for palliative reasons. He died of sepsis in 1989.

Case 2: a reactive approach to withdrawing ANH

This patient was involved in a car accident at the age of 43. After 12 days in hospital with varying levels of consciousness, she was found unconscious in hypovolemic shock with asystole and apnoea, because of a ruptured spleen. After reanimation and splenectomy, she did not regain consciousness. After 2 months in hospital, she was referred to the nursing home in a vegetative state.

In the first months, the physician administered antibiotic treatment twice for infections of the bronchial tubes. After 6 months of unchanged vegetative state, the physician and the family had lost all hope of recovery. After consulting the GP and the family, the physician

decided not to treat life-threatening complications in this patient any longer. The family accepted that decision, which was considered to be what the patient herself would also have wanted under the circumstances. However, in the first years after this decision, no life-threatening complications occurred. Compulsive crying was treated with benzodiazepines.

After 5 years, problems with the feeding tube arose. The nasogastric tube often did not run through and was regularly vomited out. Using a Percutaneous Endoscopic Gastrostomy (PEG) tube was considered. At the time, the patient survived an aspiration pneumonia without antibiotic treatment. The problems with the feeding tube increased: more vomiting, sometimes with blood, with an increasing risk of choking to death in the thick mucus. Ultimately, only a few nurses were able to change the feeding tube. Re-evaluation was undertaken at that time to evaluate whether or not the total medical treatment actually contributed to the patient's well-being. The physician concluded that continuation of medical treatment was futile and also not according to the values and wishes of the patient. A gastrostomy was considered not to be in the patient's interest and, without consent, it might be construed as an encroachment of the integrity of the human body. After consulting his colleagues, the GP, and a professor in ethics, the physician decided not to continue medical treatment and to withhold a PEG tube. It was agreed to stop all medical treatment including ANH.

On neurological grounds, the medical team assumed that she would not suffer from the discontinuation of ANH. Moreover, there was extensive experience with the physiology of normal dying processes in nursing home patients who stop eating and drinking before they die. These patients die peacefully within 1 or 2 weeks and do not show any sign of suffering.

The decision to withdraw ANH was discussed extensively with the family and the multi-disciplinary team, who thereupon gave their consent. The benzodiazepine dosage was gradually reduced to prevent withdrawal effects and replaced by a once-only depot injection of Haloperidoldecanoate because of the risk of recurrent compulsive crying.

After the tube was removed, a peaceful and tranquil phase set in for the patient and the family. The family paid intense farewell visits and their postponed mourning process could finally be completed. The patient's body gradually became less bloated. A week after removal of the tube, the patient died peacefully in the presence of her family. No one had seen any sign of suffering or discomfort. On the contrary, the family had experienced the dying process as humane and worthwhile. For this reason they consented to making this information available to others.

Case 3: a proactive approach to withdrawing ANH

The same scenario as in case 2 was applied in this case of a 44-year old man who went into a vegetative state after resuscitation for cardiac arrest. The vegetative state lasted 15 months. Flexion spasm and contractures were the main problems in this case, which made nursing care rather difficult. Passive exercises could not be done, nor was mouth care possible. An occupational therapist adapted the clothes to make nursing easier. Two hospitalizations were necessary due to problems with the PEG tube which was regularly vomited out. The patient was treated for aspiration pneumonia which occurred 6 months after admission. Only after a relapse did the family show a willingness to accept the proposal of the nursing home physician not to hospitalise the patient any more.

Each month the multi-disciplinary team discussed the main problems. The GP was consulted for coping problems in the family. The family was advised to seek support and to contact fellow sufferers. At the monthly family meetings, the physician proposed withdrawing medical treatment in the future. In case of urinary tract infections, antibiotics would be administered for palliative reasons. Because there was no more hope of recovery, the discussions about withdrawing treatment were intensified. The family was brought into contact with the family of the patient in case 2.

One year after admission, the nursing home physician concluded that all the parties concerned were ready for the decision to withdraw the ANH. Consultations had confirmed the diagnosis of the vegetative state and justified the decision to withdraw treatment. The physician made clear to the family that it was her decision to withdraw ANH. After removing the feeding tube, a depot injection of haloperidoldecanoate was given. In the first days after withdrawal, periods of smiling alternated with (motor) agitation and signs of convulsions, which were treated with benzodiazepines and neuroleptics. Eleven days after removing the feeding tube, the patient died in the presence of his family. The final phase had been difficult for them, but his wife told us 'it is better this way'. In the next 6 months, intensive meetings were held to support the family in the grieving process.

Case 4: waiting for a fatal complication

Before admission, this 15-year-old boy, who was in a vegetative state due to a traffic accident, had stayed 3.5 months in a rehabilitation centre specializing in stimulation programmes for patients in a vegetative or minimally conscious state. Because he had not regained consciousness, he was referred to the nursing home. He was fed by a nasogastric tube.

His parents visited him every day and they had not lost hope. They accepted the physician's decision not to resuscitate in emergencies, but they requested him to treat any other complications that might occur. Family meetings were planned on a regular basis to discuss medical treatment in the future.

In the first 6 months, the main problems were: contractures, constipation, two respiratory infections and repeated filamentary keratitis (Table 1). A dentist was consulted for the problems with dental hygiene and a speech therapist to reinvestigate the possibility of oral feeding, which proved not to be a feasible option. The physician decided to treat infections with antibiotics and to discuss the significance of tube feeding with the family. There were no changes in the vegetative state.

One year after admission, the physician told the family that the 'waiting phase' in which there is usually still hope of recovery had passed and he subsequently discussed the consequences. Overwhelmed with grief, the parents were not able to consider any future steps. They were not ready yet for the decision to stop all medical treatment, but accepted the decision to withhold hospitalization and curative treatment for life-threatening complications. They insisted on antibiotic treatment for infections. Meetings were held on a regular basis to prepare the family for the medical decisions in the future, including withdrawing ANH.

In the next 2 years, the situation remained stable. Another physician took over the treatment and considered inserting a PEG tube, because of repeated coughing out of the tube. He expressed his opinion as to the futility of continuing medical treatment on a patient who could not experience the benefits and again withdrawing ANH was discussed. Nevertheless, terminating treatment was no option for the family and they agreed to insertion of a PEG tube.

Almost 8.5 years after admission, the patient developed high fever with dyspnoea, due to a pneumonia. Although the physician expressed his doubts about the effect of antibiotics, the family insisted on curative treatment and on continuation of artificial feeding. In spite of the treatment, the situation deteriorated within a few days, the patient had excessive salivation, green, thick mucus, and dyspnoea. On the last day, the administration of antibiotics was stopped, and Morphine and Midazolam were given to provide relief of dyspnoea. On the fourth day after onset, the patient died in the presence of his family.

Case 5: in search of a solution

This patient has survived in a vegetative state for 16 years and never regained consciousness after hospitalization due to a traffic accident. From the very beginning, the parents had requested curative treatment of complications. In the first years, monthly family meetings

were organized by the physician and nursing staff. At each meeting the following themes were discussed: observed reactions, actual care plan with problems and actions, prognosis, goals of treatment and coping of the family. Scenarios for terminating this vegetative state in the future were discussed, of which withdrawal of the tube feeding was not acceptable to the family. Although the permanent character of the vegetative state was confirmed by a neurologist 3 months after admission, the parents did not lose hope and consulted alternative healers. They visited their son daily and spent a lot of time taking care of him. The situation led to increasing physical, psychological and social problems in the family. Support of the family was a recurring theme in the contacts between the physician and GP, but the family rejected additional professional support.

Three years after the accident, the fluid balance recovered spontaneously without the daily supply of vasopressin. At the same time, as a sign of a recovered testosterone production, his beard began to grow again. After consulting an internist, further investigations were considered futile, as the patient was not likely to regain consciousness.

The parents requested curative treatment of complications, but the physician told them that this would be futile. As the patient had never stated his own wishes as to treatment in a case like this, the physician consulted the GP, his colleagues, a neurologist, the multi-disciplinary team and the medical management of the nursing home to check his opinion about the futility of further medical treatment. The two sisters of the patient were also invited to express their views on the situation.

After these consultations in the fifth year after admission, the physician decided not to treat medical complications in a curative way any more. All consulted disciplines agreed with the palliative goals, and the parents were subsequently informed. They did not accept the decision, because they did not want to lose their son. There was a scenario for supporting the family and the team in times of crisis (e.g. when life-threatening occurred). In the first years after this decision, no life-threatening complications occurred. After 45 family meetings, it was clear that withdrawing all medical therapy would still not be acceptable to the family.

Eight years after admission, another physician took over the responsibility. An acute aspiration pneumonia which the patient developed that year was not considered life-threatening by the physician who was on duty. He supplied antibiotics at the parents' request, which led to discussions in the medical team as to whether this had been a 'missed opportunity'. Until 2003, 52 times a course of antibiotics was administered to treat infections of the urinary and respiratory tract. In the past few years, anti-epileptic agents were administered for regular seizures. The patient is still alive today.

Chapter 4

Filamentary keratitis as a chronic problem in the long-term care of patients in a vegetative state

Jan Lavrijsen, Ger van Rens, Hans van den Bosch. Filamentary Keratitis as a chronic problem in the long-term care of patients in a vegetative state *Accepted for publication by Cornea, in press*

This problem also affects the patient's relatives who keep trying to make contact by looking into the eyes of their loved ones in the hope of seeing some form of reaction

Sentence rejected by the reviewer from the following article

Dit probleem raakt ook de naasten van de patiënt die proberen contact te maken door in de ogen te kijken van hun geliefde in de hoop enige vorm van reactie te zien

Door reviewer afgewezen zin uit het volgende artikel

Filamentary keratitis as a chronic problem in the long-term care of patients in a vegetative state

ABSTRACT

Purpose

To emphasize that filamentary keratitis may occur in the long-term care of patients in a vegetative state

Methods

Clinical observation of two young patients who had survived 16 and 8½ years, respectively, in a vegetative state after an acute traumatic brain accident. Interventions were analyzed against the background of the different speculations about the relationship between filamentary keratitis and the vegetative state.

Results

Both patients' medical records registered 36 and 24 episodes of "a red eye" respectively, which in most cases were due to filamentary keratitis. The episodes lasted 1-5½ months, despite lubrication, removal of filaments and regular application of corticoid ointment. The longest remission occurred when the eyes were frequently opened, and no topical medications were applied. This experience supports the hypothesis that prolonged eyelid closure is more likely related to filamentary keratitis in these patients, more so than a moistening disturbance.

Conclusions

Filamentary keratitis can be a chronic problem in the long-term course of a patient in a vegetative state with remissions and exacerbations. These cases substantiate a relationship, although the precise mechanism is speculative. The incidence and effective treatment await further reports.

Introduction

Patients in a vegetative state have not regained consciousness after surviving a comatose phase caused by an acute brain accident of traumatic or nontraumatic origin. They show no evidence of awareness of self or the environment, an inability to interact with others, and no evidence of sustained, reproducible, purposeful or voluntary behavioral responses to visual, auditory, tactile or noxious stimuli.¹ In contrast to coma patients, however, they open their eyes and show a sleep-wake cycle; they are “awake, but not aware”.²

As a result of the relative preservation of brainstem functions, most patients in a vegetative state retain good to normal reflexive regulation of vision and eye movements, and a few may even shed tears.¹ Sustained visual pursuit is lacking in most patients, and they do not fixate on visual targets, track moving objects with their eyes, or withdraw from threatening gestures.¹ For all patients in a vegetative state, recovery after one year is unlikely.³ Because they are totally dependent, they are usually referred to nursing homes and can survive a long time on artificial nutrition and hydration

Filamentary Keratitis (FK) is a nonspecific clinical sign. Corneal epithelial filaments form as a result of a number of inflammatory or degenerative corneal conditions. A corneal filament consists of a tag of elongated epithelium that is firmly attached to the base but has broken away from the cornea. The epithelial filament is intertwined with mucus and degenerative cells. Filaments stain both with fluorescein and with rose Bengal. They often fall off with time but tend to reoccur.⁴

Because medical facts about the long-term care of patients in a vegetative state are scarce in the literature, we have studied the medical events of all patients in a Dutch nursing home who had spent over a year in a vegetative state after an acute brain accident. FK was a remarkable finding in two patients from the total caseload of five who met the criteria for vegetative state, as formulated by the Multi Society Task Force on Persistent Vegetative State.¹ The FK was diagnosed by two independent ophthalmologists in different hospitals. Both patients were examined by the first author (J.C.M.L.), the patient in case 1 was also examined by the second author (G.V.R.)

Because of the lack of literature on the relation of FK to the long-term survival in a vegetative state, we present these two case reports

Case reports

Case 1

This male patient has survived in a vegetative state since 1987, when he was involved in a motorbike accident at the age of 18. Five months after the brain accident, the ophthalmologist diagnosed FK of the right eye as a cause of a red eye. Lagophthalmos the right eye was suspected, and artificial tears were applied. However, observation in the nursing home showed no lagophthalmos. A second visit two weeks later showed persistent FK with subepithelial ingrown blood vessels in the cornea. Fluorescein staining confirmed the diagnosis of FK, and a Schirmer tear test in both eyes was normal. Corticoid/antibiotic ointment was included in the therapy. As the keratitis was considered a moistening disturbance of the eye at the time, artificial tears were applied continually to prevent the recurrence of corneal problems. This therapy had only a temporary effect on the FK.

After this, the nursing home physician registered 36 episodes of a “red eye”: 6 times a conjunctivitis/blepharitis cured by antibiotic/corticoid therapy, 13 times a nonspecified ‘red eye’, and 17 times FK. The problem usually began with signs of conjunctivitis (vessel dilatation and discharge), which did not improve after the application of corticoid/antibiotic ointment. Cultures showed no clinical significant results and mycosis was excluded. The episodes of keratitis lasted 1-5½ months, in which FK was seen mainly in of the right eye in the first 5 years, and more in the left eye in the following 10 years.

Five years after admission, during the fifth relapse of keratitis, superficial infiltrates and pannus as well as superficial stromal vessels were observed in the right eye, and FK in the left eye. After topical ofloxacin was prescribed, the infiltrates and filaments disappeared within a week, but there was no effect on the blood vessels in the cornea. The therapy with artificial tears was continued.

The nursing home physician and two ophthalmologists informed the parents and discussed the therapeutic options at the time. The family rejected occlusion of the eye and the proposal to apply a permanent wear soft lens as bandage.

Seven years after admission and after consulting a cornea specialist, the ophthalmologist removed the filaments under local anesthesia. Later on, the nursing home physician repeated this procedure. In some years, FK was a main medical and nursing problem.

In 2002, after 15 years in a vegetative state, a vague nebulae cornea with pannus and superficial stroma vessels was observed in the right eye, and ingrown blood vessels without filaments in the left eye. Because the problem could not be solved permanently in a wet eye

and the patient's eyes seemed to be more often closed than open, we changed our hypothesis, which was based on a moistening disturbance as well as the therapy. Our current hypothesis is that FK could be caused by insufficient opening of the eye, resulting in a lack of refreshment of the tear film. Therefore, the lubricants were withdrawn, and the family and nursing staff were advised to open the eye frequently. After this intervention, the FK has not reoccurred in 25 months, the longest remission in this survival of more than 16 years in a vegetative state.

Case 2

This patient, who was involved in a traffic accident at the age of 15, survived in a vegetative state from 1991 until 2000. During this survival, he had been well fed by tube feeding and had shown tears. Before admission to the nursing home, an ophthalmologist had diagnosed FK as a cause of an opaque left cornea, which was treated with corticoid/ antibiotic ointment.

At the time of admission, dexamethasone/neomycin was applied in his left eye because of a relapse of FK with superficial blood vessels ingrown in the left cornea. From 1993 until 2000, 24 episodes of a 'red eye' OS were registered in the medical record, most times caused by FK. In certain periods, the cornea was opaque. In every episode of conjunctivitis and keratitis, antibiotic/corticoid ointment was applied, which usually proved temporarily successful in reducing the inflammation and filaments within 2-4 weeks and in one instance, within 6½ weeks. Between these episodes, daily observations showed no red eyes, and artificial tears were applied in both eyes.

From 1995 onward, the nursing home physician regularly removed the filaments mechanically from the cornea under local anesthesia. Once a culture was made because the turbid filaments looked like pus, this turned out to be sterile.

The patient died in January 2000.

Discussion

In these young patients with long-term survival in a vegetative state, FK turned out to be a chronic problem with remissions and exacerbations. In 1927, FK was described in some cases of chronic arthritis.⁵ Since then, many conditions have been associated with filaments, including dry eyes, prolonged occlusion or ptosis, ocular surgery, recurrent corneal erosions, infections, and diabetes mellitus.^{6,9}

In a review article some authors stated that the absence of normal lid movements predisposes the cornea to chronic filament formation in the long-term course of hospitalization due to brain injuries.¹⁰ Brain stem injuries can be associated with FK, but only two previous case reports are available about coma in the first years.^{6 11} It is difficult to compare these reports with our cases of long-term vegetative state, because the vegetative state was not defined and the cause was not described in them. Moreover, in contrast to coma, in patients in a vegetative state, the function of the brainstem is completely or partially preserved; the main problem is absence of function in the cerebral cortex.^{1 2}

In our cases and in the literature, there is no evidence that absence of tears is a cause of FK in patients in a vegetative state. At first, we assumed that the eye would be too dry as a result of infrequent blinking. For that reason, artificial tears were supplied on a regular basis. This, however, did not prevent recurrence of the problem, and neither did additional debridement of the filaments, as suggested by several authors.^{4 12}

One case study we found describes the treatment of FK with a soft contact bandage lens in a patient who was comatose for 10 months.⁶ However, in that case the vegetative state was not described and there was no long-term follow-up. After an initial positive effect, the lenses frequently came out, and the patient died 4 months later. The parents in case 1 rejected this therapy.

Because the problem could not be solved permanently in a wet eye, we based our last intervention on the literature on the relationship of FK to ptosis, prolonged patching, or eyelid closure.^{8 13} Moreover, on the basis of heteroanamnestic information, we came to the conclusion that our patients' eyes were probably far more often closed than open, even outside the FK episodes. On the basis of the theoretical assumption that FK could be caused by a lack of refreshment of the tear film, we terminated the treatment with artificial tears and began to open the patient's eyes frequently. Until now, the FK has not reoccurred.

As medical facts about the long-term course of the vegetative state are scarce, it may be assumed that general practitioners and nursing home physicians do not recognize FK as such. Moreover, a red eye can easily be attributed to only conjunctivitis, which frequently occurs in these patients, as seen in these two cases. It is not unlikely that the different problems such as blepharitis, conjunctivitis and FK are all part of the same process.

In conclusion, this finding of FK in two patients in a vegetative state highlights a chronic problem in the long-term care of these patients. We recommend consulting an ophthalmologist in every case of a chronic red eye in vegetative state patients. Reports of such cases and effective therapy may help us gain more insight into the problem.

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Chapter 5

Diagnosis of vegetative state as a basis for
medical treatment on the borderline between
life and death

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Vegetative state is perhaps the least understood and most controversial disturbance of consciousness.

Vegetatieve toestand is wellicht de minst begrepen en meest controversiële stoornis van het bewustzijn.

Joseph T. Giacino. *Seminars in neurology* 1997;17:108

Diagnosis of vegetative state as a basis for medical treatment on the borderline between life and death

ABSTRACT

- The term 'vegetative state' is most appropriate for the state which develops when patients open their eyes after a comatose phase, without regaining consciousness
- The definition and the diagnostic criteria from the Multi Society Task Force on Persistent Vegetative State are usable for the clinical practice in the Netherlands
- The vegetative state must be differentiated from coma, locked-in syndrome and Minimally Conscious State
- A systematic, multidisciplinary approach under the direction of a physician is key to diagnosing vegetative state. To this end, a clinical assessment is recommended with reassessment and verification of the diagnosis at appropriate moments
- Careful observation remains the fundamental to the diagnosis

Introduction

Patients with acute brain damage have nowadays a better chance of surviving a comatose phase. The larger part of them regain consciousness, but there is also a category of patients that do not. These patients usually open their eyes after 2-4 weeks, and a sleep-wake cycle sets in, they are 'awake, but not aware'.^{1 2} Characteristic of these patients is the absence of a functioning cerebral cortex, as shown by behavioural observations. On the basis of the first description of this condition by Jennett and Plum in 1972, the Dutch Health Council proposed the term 'vegetative state' in 1994, and developed medico-ethical and legal frameworks for policy.³

A proper diagnosis is a prerequisite for careful decision-making with regard to these patients. There are indications that the diagnosis is not always made adequately.^{4 5} Misinterpretation of terminology, inexperience of researchers, and lack of time play a role here.⁴

This was the reason why we decided to develop a diagnostic concept for the medical practice on the basis of current knowledge, and from a multiprofessional angle. How, by whom, and when is the diagnosis 'vegetative state' made as accurately as possible with the use of unequivocal terminology and criteria?

To answer this question one of the authors (J C M L) conducted a literature search and various points were discussed at an expert meeting (all authors) Prior to inviting the participants, we consulted the Netherlands Centre for Brain Injury and the medical professional organizations

Terminology

Although after the introduction of the term ‘vegetative state’ by Jennett and Plum various names were still used, ‘vegetative state’ is the term that took best root in the scientific literature^{6 7} Additions such as ‘acute’, ‘continuous’, ‘permanent’ and ‘persistent’ result in a confusing linkage of condition and prognosis^{3 6 8}

In the Netherlands, the Health Council used the translation *vegetatieve toestand* to replace previous names such as *coma vigil*, *chronische coma*, *langdurig coma*, and *vegeterende toestand*³ We think this term may be useful in practice as a descriptive diagnosis Anyone who wants to say something about the prognosis, may mention the time lapse following the occurrence of the brain damage

We choose to use the internationally much used definition of the American Multi-Society Task Force ‘Vegetative state is a clinical condition of being fully unconscious of oneself and the environment, with sleep-wake cycles and full or partial preservation of autonomous functions from the hypothalamus and brain stem’⁹ We also advocate the use of the corresponding diagnostic criteria from Table 1, which by now have been accepted by various groups of experts^{7 9 10}

Differential diagnosis

The vegetative state needs to be differentiated from coma, locked-in syndrome and a minimally conscious state

Coma patients do not show a sleep-wake cycle, have their eyes permanently closed, and there is no interaction with the environment²

The locked-in syndrome is one of the major diagnostic pitfalls As a result of injury to the ventral part of the pons, there is serious paralysis of the voluntary motor system with intact consciousness² Observations reveal that vertical eye movements and blinking are often still possible the patients are awake and conscious

Table 1. Criteria for vegetative state ⁹

-
1. No evidence of awareness of self or environment and an inability to interact with others
 2. No evidence of sustained, reproducible, purposeful or voluntary behavioural responses to visual, auditory, tactile or noxious stimuli
 3. No evidence of language comprehension or expression
 4. Intermittent wakefulness manifested by the presence of sleep-wake cycles
 5. Sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care
 6. Bowel and bladder incontinence
 7. Variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes
-

Multi Society Task Force on PVS

Finally, there is a group of patients with a sleep-wake rhythm and minimal signs of conscious response. Although this response is inconsistent, it is reproducible or consistent enough to differentiate it from a reflex response.¹¹ The proposal of an international expert group to call this state ‘minimally conscious state’ is still the subject of discussion.^{7 11 12}

Diagnostic assessment

From 1974 on, the Glasgow coma scale (GCS) has been used to assess the level of consciousness of patients (Table 2).¹³ This scale was originally developed for the acute phase. Its use for the follow-up phase makes valid comparisons with earlier findings possible. One disadvantage of the scale is that there is little room for meticulous assessment of the situation of patients emerging from a coma or vegetative state (GCS score better than E4-M4-V2)^{3 15} For this purpose, multiple standardised research tools were developed, including the Western Neuro Sensory Stimulation Profile (WNSSP).¹⁵⁻¹⁸ These can be used to answer the question whether someone is in a vegetative state and to what extent there has been recovery.

We propose a diagnostic assessment based on the GCS and with the systematic structure of the WNSSP, which will be feasible and reproducible in clinical practice for the operationalisation of the diagnostic criteria from Table 1. Essential in this is a multidisciplinary approach under the direction of a physician.

Table 2. Glasgow Coma Scale (GCS) ^{13 * †}

Score	E: Eye Opening	M: Best Motor Response	V: Best Verbal Response
1.	none	none	none
2.	to pain	extending	sounds
3.	to speech	flexing-abnormal	words
4.	spontaneous	flexing-withdrawal	confused
5.		localising	orientated
6.		obeying commands	

* - Choose the best obtainable score, left or right.¹⁴
- Apply painful stimuli to arms or supraorbitally, not to legs.
- Differentiate M = 6 from grasp reflexes by, for example, asking the patient to open his/her hand too
- Score M = 5 if, in response to a supraorbital stimulus, the patient raises his/her hand past the chin, or if in response to a nail-bed stimulus, the other hand passes the median line.
- Score M = 3 instead of 4 if during flexion of the arm two of the following criteria are also met: extension of the legs, occasionally also endorotation of the arm, interposition of the thumb between the fingers, maximal flexion of the wrist.¹⁴

† The maximum score for vegetative state is E4-M4-V2.³

Medical investigation.

Analysis of the medical history makes clear whether there were any problems with the nerves, senses and/or motor system prior to the brain damage. Neurological and imaging data on the acute phase provide insight into the nature and extent of the brain damage. The heteroanamnesis provides additional information on the cause of the brain damage.

The patients' general conditions are important for their possible effect on the outcome of the assessment. This is particularly the case for nutritional state, medication and impeding complications such as contractures.¹⁹ To achieve the best possible state of alertness in patients, the administration of sedatives must be discontinued as far as possible. For the same reason patients can best be examined in a sitting posture.¹⁹ Splints that are a hindrance should be removed. There is a possibility of delayed response during the examination and of fluctuations in the clinical picture.^{17 19} Most patients can be better examined in the morning than in the afternoon.¹⁷ What is also required is a stimuli-poor examination room and at least half an hour rest before examination. Video recordings may be useful in order to assess responses carefully.

The general physical and neurological examinations provide information on the patients' physical conditions and a number of diagnostic criteria such as brain-stem reflexes and autonomic functions.

The first three criteria from Table 1 can be investigated with the help of the GCS (Table 2) and functional examination (Table 3).

Table 3. Functional examination of a possible PVS patient *†

general	spontaneous response periods of wakefulness during examination eye contact attention to commands
auditory response	to the voice of the examining physician to sound (bell outside field of vision) to verbal commands (hand extension, opening/closing of the mouth, putting out the tongue, opening/closing the eyes, raising the eyebrows, moving some part of the body)
expressive communication	best verbal response (see Table 2) facial expression body language yes/no response to 3 biographical questions
visual response	blinking on request visual tracking (of a person, mirror, photograph or object) presentation of said verbal commands in large typeface
response to tactile stimuli	tapping on shoulder brushing lips with a cotton swab or toothbrush holding familiar objects in hands (ask the patient to show you how they are used)
response to personal	photographs, music, scents, tastes, objects preferences (not standardised)

* Adapted from the Western Neuro Sensory Stimulation Profile (WNSSP).¹⁶
† Differentiate between: no response, undifferentiated response – such as yawning, increase in breathing, and non-specific movements – and differentiated response such as purposeful movements.

There are also necessary contributions from other disciplines. In nursing, 24-hour reporting is available. Physiotherapists, occupational therapists, speech therapists and neuropsychologists with experience with this type of problems may specifically be deployed to assess the situation as regards motor function, posture, swallowing and oral motor function, and behavioural characteristics respectively.

Information from people close to the patient is essential because they are often the ones who spend the most time with the patient and know his or her body language well¹⁷ They are able to indicate the best responses that they observe in the patient in various sensory areas In some cases it may be useful to let them carry out parts of the examination and to observe the patient and his/her family yourself¹⁷

Interpretation

A vegetative state exists when there are no signs of sustained, reproducible, purposeful or voluntary behavioural response, and the patient meets the criteria from Tables 1 and 2 (maximum score E4-M4-V2)

The physician must be able to differentiate between involuntary response, such as a programmed reflex integrated at spinal or stem level, and voluntary response as a sign of consciousness²⁰

It is essential to distinguish between observed behaviour and interpretation, especially where others are involved²¹ This is particularly the case for squeezing the patient's hand (see Table 2) and the distinction between watching/tracking and staring Physicians should always test the information from reports against reproducibility themselves In this context the interpretation of visual tracking is subject to debate²² It may be a first sign of recovery from a vegetative state, but if there are no other indications of mental functioning, it is not proof of consciousness^{6 23}

Although 'localisation' (M=5) means that the patient is no longer in a vegetative state, the signs indicating this may be vague and few and far between In such a case we advocate an additional observation period of at least 6 weeks in order to see whether any recovery that may occur will persist

Additional examination

As yet, additional examination using advanced medical technology has not been able to confirm the diagnosis 'vegetative state'^{3 7 9} The contributions from EEC, CT scans and MRI are not specific for vegetative state, although, in differential diagnosis with locked-in syndrome, an MRI scan can reveal an infarct in the ventral part of the pons⁹

The examining professional

It will be clear that the assessment should be made by an expert experienced in the examination of patients with serious brain damage and consciousness disorders.^{3 7 24} The Dutch Health Council prefers assessment by different physicians.³ In Great Britain, this is specified as two experienced physicians.²⁵ Moreover, the emphasis is on the significance of a second opinion before taking major treatment decisions such as ceasing treatment.⁷

We think the diagnosis should be made by a physician experienced in the examination of patients with consciousness disorders. In the acute phase, that will be the neurologist or neurosurgeon; in the follow-up phase, the treating physician should repeatedly test the diagnosis. In this context we consider a systematic, multidisciplinary approach under the direction of a physician more important than the number of doctors involved. If there is doubt or if major treatment decisions are in order, we recommend having the diagnosis tested by an independent experienced expert.

Times of assessment

After the diagnosis has been made, periodical reassessment is deemed important, but specific recommendations are lacking.³ In line with the policies in a number of specialised rehabilitation clinics, we consider an initial term of at least six weeks necessary for a multidisciplinary team to realise the approach described here.^{5 26} Within this term, a minimum of 4 moments should be planned: shortly after admission and every 2 weeks.

There is a reasonable amount of agreement in the literature on the question as to the terms within which there is still a chance of the vegetative state improving. Generally, a period of 3 months is observed after non-traumatic brain injury, and one of 12 months after traumatic brain injury.²⁷ In the Netherlands, the Health Council observes a wider margin of 6 months after non-traumatic brain injury.³ We recommend reassessment and verification of the diagnosis at these prognostically important moments after 3, 6 and 12 months in order to confirm the diagnosis and thus mark a new phase in the treatment plan.

It is essential that this demarcation and the prognosis are discussed with all those involved, also in view of the consequences for medical policy. Other appropriate moments for reassessment: when changes in the patient's condition occur, when other physicians take over the case, and prior to major treatment decisions such as ceasing treatment.

Conclusion

Thirty years after the first description, there is agreement on the term 'vegetative state'. Without a 'golden standard', diagnosis can only be made by repeated, careful clinical assessments. Alertness is called for, particularly in differentiating between the locked-in syndrome and a minimally conscious state.

Cooperation with other disciplines and with the patients' families is obligatory, embedded in a systematic, multidisciplinary approach under the direction of a physician. If there is doubt and also prior to major treatment decisions, we recommend having the diagnosis tested by an independent expert familiar with this type of problem.

Thus, observation skills are still of central importance in diagnosing 'vegetative state'. The tradition of clinical assessment as initiated by Hippocrates is therefore still very much up-to-date. Furthermore, the clinician can now enlist the services of a multidisciplinary team.

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Chapter 6

Prevalence and characteristics of patients in a vegetative state in Dutch nursing homes

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De N= 1 studie is het ultieme vaarwater van de geneeskunde: het is de bron van alle onderzoek en het einde: de toepassing in de praktijk.

The N=1 study is the ultimate territory of medicine: it is the source of all research and the end: the implementation in practice.

Prof. dr. R. Holdrinet. *Medisch Contact* 2002;57:1514

Prevalence and characteristics of patients in a vegetative state in Dutch nursing homes

ABSTRACT

Objectives

To establish the prevalence of vegetative state in Dutch nursing homes, describe the patient characteristics, and highlight the possible influence of medical decisions at the end of life

Design

A cross-sectional survey The vegetative state was defined according to the Multi Society Task Force on PVS All Dutch nursing homes were approached to provide on patients in a vegetative state In case of doubt, the researcher discussed the diagnosis with the patient's physician and, if necessary, examined the patient Information on patients in vegetative state in care between 2000 and September 2003 and end of life decisions for them were also recorded

Results

All nursing homes and physicians participated After assessment of 12 doubtful patients, 32 met the criteria of vegetative state lasting longer than one month, a prevalence of 2 per million people Of these, 30 patients' data were analysed age 9-90 years, 73% female, duration of vegetative state 2 months-20 years (26 surviving > 1 year, 13 > 5 years) Stroke was the commonest cause Between 2000 and September 2003, there were 76 patients in a vegetative state in care of whom 34 died of complications and nine after withdrawal of artificial nutrition and hydration

Conclusions

The prevalence of vegetative state in Dutch nursing homes has been established for the first time The figures are lower than suggested in the literature The study included a heterogeneous group of patients, of which a substantial number survived for many years The results cannot be explained by a policy of systematically withdrawing artificial nutrition and hydration

Introduction

Patients who do not regain consciousness after a comatose phase following acute brain damage can end up in a vegetative state (VS), showing a sleep-wake cycle without any signs of awareness.¹ Their fate has been described as a 'fate worse than death'.^{2,3} Over the past ten years, international working groups have provided more clarity on terminology, diagnosis, prognosis, and the care of these patients.^{4,6} Required care is intensive and complex, and the medico-ethical dilemmas in treatment decisions increase as the chances of recovery become doubtful.⁷ Recovery from a vegetative state becomes unlikely once this state persists for some time, that is, longer than 12 months after trauma or three to six months in the case of non-traumatic brain damage.^{5,8,9} In such a context, single cases may draw world-wide media attention.¹⁰

Surprisingly, little is known about the exact number of patients in a vegetative state or their medical history in long-term care.¹¹ Confusion about terminology and a lack of accepted diagnostic and inclusion criteria are contributing factors,⁶ and this is reflected in the variation and wide range of reported estimates of prevalence, from 5 to 140 cases per million people.^{4,6}¹¹ However, with the current background knowledge it is possible to conduct accurate research on the prevalence. This is important to assess the implications of the problem from a realistic perspective and to plan specialised care facilities and develop better care.

The complex long-term care provided by nursing homes makes these institutions most suitable for a survey of patients in a vegetative state. However, the available data are rather limited, particularly with regard to nationwide populations of nursing home patients in a vegetative state after acute brain damage. A few studies have included a (local) hospital population,^{12,13} others have included patients with developmental disorders or regressive-degenerative disease.^{14,15}

The special circumstances in the Netherlands provide an excellent opportunity for a prevalence study as there are more than 330 nursing homes for a population of 16.2 million people and these are well distributed throughout the country.^{16,17} Professional care is standardised and provided via multidisciplinary teams, which are led by specialist nursing home physicians.¹⁸ A multidisciplinary guideline for the diagnosis of the vegetative state has recently been published.¹⁹ This specialised care is necessary to deal with the complex dilemmas of the vegetative state, including decisions about the withdrawal of treatment and artificial nutrition and hydration (ANH).^{9,20}

Therefore the present study aimed to investigate the prevalence of patients in a vegetative state after acute brain damage in all nursing homes in the Netherlands and to

describe the main characteristics of these patients. We also aimed to highlight the possible influence of medical decisions at the end of life in the years before the study.

Methods

We conducted a cross-sectional survey with a three-step design (see fig 1 Results) of the number of patients in a vegetative state in all Dutch nursing homes.

In *step 1*, we sent a letter to all the nursing home physicians of all nursing homes and long-term nursing care facilities (n=380) in the Netherlands informing them about the study. The first author (JL) then contacted them by telephone for an inventory of all probable cases of vegetative state in care in September 2003. The vegetative state was defined according to the criteria of the Multi Society Task Force on PVS and an article explaining this, based on a literature study and an expert meeting, was also sent with the letter.^{4 19} We directed our survey at patients in a vegetative state for at least one month after acute brain damage. Patients with degenerative disease as a cause (for example dementia) were excluded, since the diagnosis of vegetative state in Alzheimer disease has proved to be not easy and is subjective.²¹ Moreover, the characteristics of these patients and the medico-ethical dilemmas involved are different. During the telephone interview, the nursing home physicians were also asked to provide information on those patients in a vegetative state who were cared for between January 2000 and September 2003 and who had recovered and/or left the nursing home before 1 September 2003. We collected data on the end of the management of the episode of the vegetative state: recovery and/or discharge, death from co-morbidity despite treatment, death from co-morbidity after a non-treatment decision, or death from dehydration after withdrawal of ANH. The nursing home physicians were asked to consult their medical records and colleagues and provided the information during the telephone interview or afterwards by email.

In *step 2*, for each of the patients probably in a vegetative state in September 2003, the nursing home physician directly responsible for the patient's care completed a questionnaire consisting of 10 items: sociodemographic data (date of birth, sex, marital status, place of residence before admission), medical history (date of brain accident, cause of brain accident, hospital diagnosis at discharge and manner of (tube) feeding), and consensus on the diagnosis with the multidisciplinary team and family, explained by no signs of consciousness, purposeful reactions or communication. There was one item on the direct effects of medication and metabolic disturbances on consciousness, which had to be ruled out. The last item was in accordance with recent guidelines.⁸ The first author checked the clinical

information in the collected questionnaires against diagnostic criteria for the vegetative state and sought clarification where needed

In *step 3*, in those instances where doubt about the diagnosis remained, the first author or two other experts assessed the patient. We chose the Western Neuro Sensory Stimulation Profile (WNSSP) as our structured assessment instrument^{22 23}. The family and physician were invited to be present during the assessment. Information on the patient's functioning was obtained from family or caregivers and, when instructive, their interaction with the patient was observed. Afterwards, we provided feedback about the diagnosis to the physician and the family.

The questionnaire survey and all assessments were carried out with the written informed consent of the families concerned. The questionnaires were rendered anonymous. In five cases, the physician failed to return the questionnaire but responded after being sent a reminder. The family of one patient with doubts about the diagnosis did not consent to further investigation and this patient was therefore not included in the study.

We submitted the research protocol to the local Research Ethics Committee for approval. However, according to the committee the study did not need ethical approval because it was not medical scientific research according to the criteria of the Dutch Medical Research Involving Human Subjects Act.

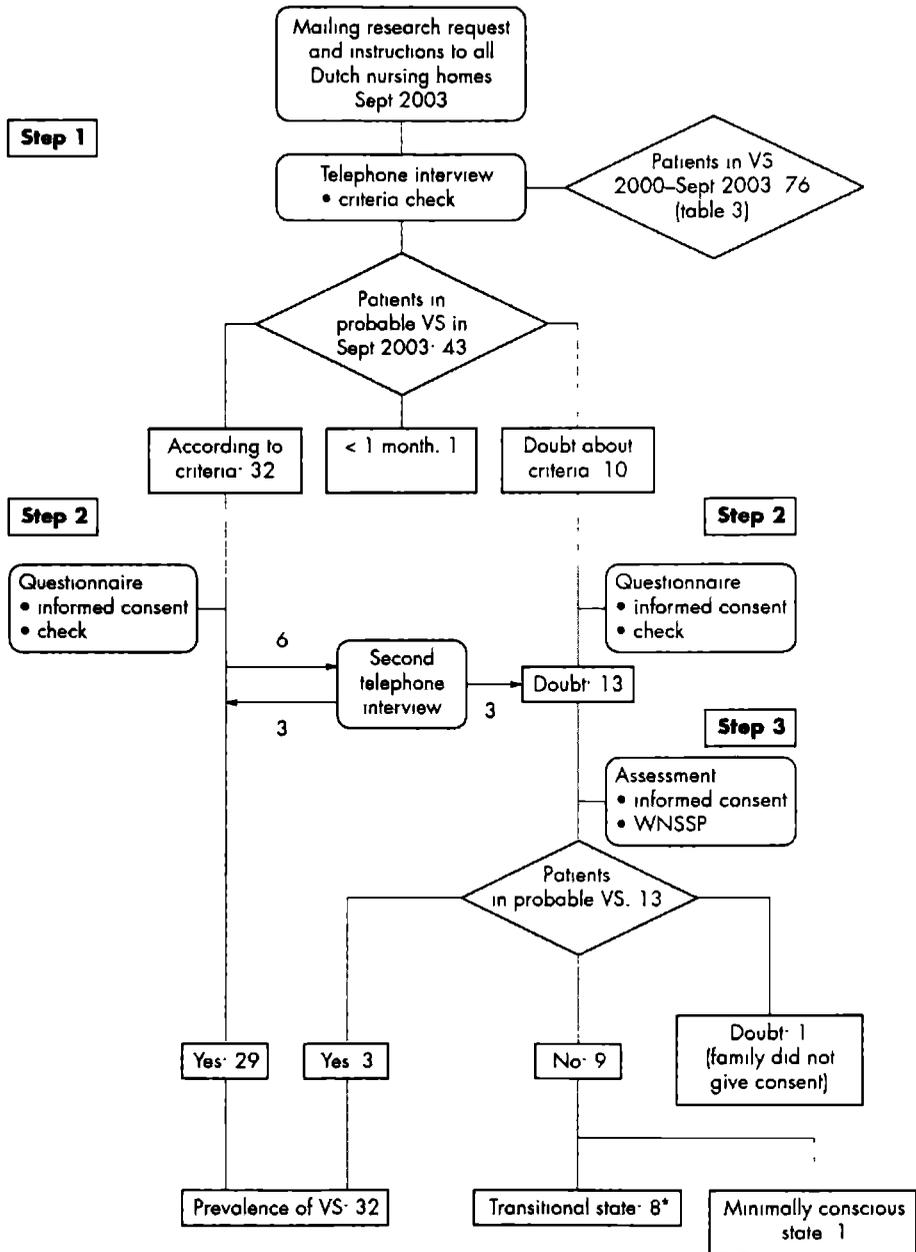
The results were statistically analysed using SPSS 11.0.

Results

Prevalence

The results are shown in fig. 1. All the nursing homes in the Netherlands and the nursing home physicians participated in the study. Initially, we identified 43 possible patients in a vegetative state. One patient in a transfer unit of a nursing home in a hospital was excluded because the duration of vegetative state at the time of the study was less than one month.

Figure 1: Flow chart of research design



* Criteria 'transitional state': sleep-wake pattern, being awake for a major part of the day; generally more definite localising to visual, auditory or tactile stimulation; tracking eye movements following objects or people; may show emotional responses to presence of family; may smile or cry. ⁶

After checking the questionnaires, the diagnosis was in accordance with the criteria in 29 patients, but there was some doubt about the diagnosis in 13 patients. One patient could not be assessed because the family refused consent. In the remaining 12 patients, the diagnosis of vegetative state was confirmed in three patients, whereas eight were classified as being in a 'transitional state',⁶ and in one patient a Minimally Conscious State was observed (in which the patient has the ability to follow simple commands).²⁴ This resulted in a total number of 32 patients in a vegetative state in nursing homes all over the Netherlands at the time of the study.

As the total number of nursing home beds in 2003 was 62,331, this resulted in a prevalence of 5.1/10,000 nursing home beds. For the Dutch population of 16.2 million, this means a prevalence of 2 per million people.

Characteristics of the patients in a vegetative state

The data of two of the 32 patients correctly diagnosed as in a vegetative state were not available as the families did not consent to the provision of data. Most patients (73.3 %) were female, and the mean age was 52.6 years (range 9-90; table 1). Six of the eight trauma patients were under 40 years.

The mean period of unconsciousness since the brain incident was six years, ranging from two months to 20.3 years. Most of the patients came from hospitals, and stroke was the commonest cause of the vegetative state (14/30), particularly in patients older than 70 (n=9). With the exception of one patient, all stroke patients were female.

For two trauma patients, the post-traumatic survival period was less than a year and for two stroke patients the survival period was less than six months after the event. The majority of patients (n=26) had survived for more than a year: eight patients between five and 10 years and five more than 10 years (16.7%). This means that the prevalence of patients in a vegetative state for more than a year is 1.6 patients per million.

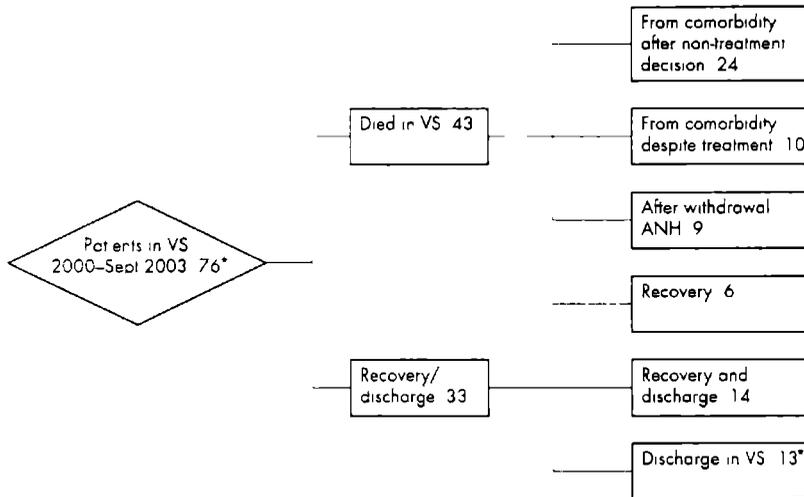
All but one patient received tube feeding. Five patients had a nasogastric tube (three having been in a vegetative state for more than five years and one for more than 16 years).

The results of the telephone survey of patients in a vegetative state between January 2000 and September 2003 are shown in fig 2. During that period, 43 patients died: 10 because of complications despite treatment, 24 because of complications after a non-treatment decision, and 9 after the withdrawal of ANH.

Table 1: main characteristics of patients in a VS (n=30, 2 missing)

Variable	Mean 52.6 years	Sd 22.2	Median 51.5	Min 9	Max 90				
Age	Years	No	%						
	0-40	11	36.7						
	41-60	7	23.3						
	61-80	8	26.7						
	> 80	4	13.3						
Gender distribution	<30	30-39	40-49	50-59	60-69	70-79	80-89	90-99	Total
Females	3	3	4	1	3	3	4	1	22 (73.3%)
Males	2	2	1	2	0	1	0	0	8 (26.7%)
Marital status	Not married	12	40						
	Married	12	40						
	Divorced	5	16.7						
	Widowed	1	3.3						
Admitted from	Hospital	26	86.7						
	Rehabilitation centre	1	3.3						
	Home	2	6.7						
	Other nursing home	1	3.3						
Cause VS	Trauma	8	26.7						
	Stroke	14	46.7						
	Anoxia	7	23.3						
	Other	1	3.3						
Duration VS	Months	No	%						
	0-6	3	10						
	6-12	1	3.3						
	12-60	13	43.3						
	60-120	8	26.7						
	> 120	5	16.7						
For all patients		30	mean 72.2 months (median 50.7, Sd 68.5, range 2.1-244.1)						
For patients aged 0-40		11	mean 90.1 months (median 91.8, Sd 77.7, range 2.6-232)						
For patients over 70		10	mean 62.1 months (median 45.3, Sd 58.7, range 2.1-187.2)						
Tube	PEG	24	80						
	Nasogastric	5	16.7						
	No tube	1	3.3						

Figure 2: Patients in VS in 2000-Sept 2003



* One of the 13 patients was discharged to another country, 12 to other Dutch nursing homes. Of 3 of these patients was known that they had died in a nursing home after discharge. Without these double counts the total number of VS patients was 73. Double counts of other 9 patients cannot be excluded in the total number.

Discussion

This is the first study on the prevalence of the vegetative state that covers a total population of nursing home patients. Most of the 32 patients had survived more than one year in a vegetative state and a substantial number even more than 10 years, which emphasises the long-term care for this group of patients.

The strong points of our study include the participation of all nursing homes in the Netherlands and a full response from the nursing home physicians. Contrary to most other studies, we used uniform definitions, and strict inclusion criteria and assessment procedures based on updated international standards.^{4,8,19} Moreover, we involved the patients' families in the assessment when there was doubt. Thus, among 12 patients, we identified eight who did not respond to commands, but reacted emotionally to their family and/or could fixate on objects and follow them with their eyes. The International Working Party on the Management of the Vegetative State had discussed this category of patients but not reached consensus whether this stage should be considered vegetative or non-vegetative.⁶

In the Netherlands, patients in a vegetative state are admitted to nursing homes for long-term care. Home care for these patients is exceptional. From this one may conclude that the prevalence of the vegetative state in the present study is low. There are only a few reports available for comparison. In 1991, approximately 3% of the patients from four Milwaukee nursing homes were identified as being in a vegetative state¹⁵. However, that study also included patients with dementia, and therefore the figures cannot be compared. A recent survey of 48 hospitals and 44 nursing facilities in Vienna showed a prevalence of 32 patients in a vegetative state, corresponding to a prevalence of 19 patients per million¹³. That study of a local population with the same absolute number of patients in a vegetative state as was found in our study confirms that this number can be considered as low. Our findings are comparable with those of Minderhoud and Braakman,¹² who reported 53 patients in a vegetative state for longer than six months in Dutch hospitals and nursing homes in 1983. However, in that study the response of nursing homes was low. In 1994, by extrapolation of data from a limited number of nursing homes, the Netherlands Health Council estimated the total number of patients in a vegetative state in the Dutch population to be between 100 and 200⁹. The difference between that extrapolated prevalence and our findings may be explained by the different methods of establishing the prevalence (extrapolation versus real prevalence) and/or a change in medical decisions for these patients after 1994. Since that time, reports of the Health Council and the Royal Dutch Medical Association have concluded that it is justifiable to withdraw life-sustaining treatment, including ANH, when the chance of recovery is negligible^{9,25}.

However, there is no evidence that the low prevalence of vegetative state in this study reflects a policy of systematically withdrawing ANH. Firstly, our survey shows that a substantial proportion of the patients in a vegetative state were under care for more than five or even ten years, which seems commoner than reported in previous studies⁵. ANH was apparently continued for these patients for all these years. Secondly, the retrospective part of our study (see fig 2) indicates that, in the three years before this study, only nine of 43 patients in a vegetative state had died due to the withdrawal of ANH. These data should be interpreted with caution, as the diagnosis of vegetative state had been established retrospectively. Nevertheless we think that the nine patients in whom ANH was withdrawn provide a realistic picture. The impact of the diagnosis vegetative state in relation to withdrawing ANH is high for everyone involved and we assume that the recollections of the nursing home physicians are reliable. Thus the withdrawal of ANH cannot account for the low prevalence and in our view co-morbidity and not-treatment decisions for co-morbidity

(the common cause of death reported) seems to be a better explanation. This finding supports the view that physicians prefer to manage patients in a vegetative state by not treating life-threatening co-morbidity, rather than by withdrawing ANH²⁶

Other explanations for the low prevalence include exclusion of dementia and a transitional state. The fact that we did not include hospitals and households could have resulted in an underestimation of the total prevalence in the Netherlands. It is likely that a number of patients were still in hospital prior to their transfer to a nursing home, although patients in transfer units of nursing homes in hospitals were included.

In our survey most patients in a vegetative state survived the crucial one year period after which recovery of consciousness is unlikely for all causes⁵. There were only four patients for whom recovery could not be ruled out at the time of study based on the prognostic crucial period of 12 months for traumatic vegetative state and six months for non-traumatic vegetative state. We recorded prolonged survival in elderly as well as in younger patients. The sex distribution in our study contrasts with the male preponderance reported in the Vienna survey¹³. The fact that there were nearly three female for every male patient in our study is mainly because of the influence of status after stroke in our nursing home population. The average age of 52.6 years is young for a nursing home population. This perhaps indicates that the parents of patients in a vegetative state may be involved in decision making rather than children, as is usually the case in nursing homes. Virtually all patients received ANH, as is known from other studies¹⁵. The use of nasogastric tubes in current long-term care is remarkable considering their complications. Recently, research into events and decision making in the long term care of such patients showed that withdrawal of ANH can be an acceptable scenario for letting the patient die, although this scenario cannot be applied in all situations⁷.

We have established accurately, for the first time, the prevalence of vegetative state in a nursing home population. We recommend that our survey be repeated to monitor developments in prevalence and to analyse factors which influence the figures. The use of uniform criteria is essential, and for that purpose we recommend classifying patients in a 'transitional state' as not being in a vegetative state. The use of a standardised assessment instrument can be recommended to clarify such cases, although direct observation with participation of the family is important as well. Further research on this recently identifiable category is necessary because the medico-ethical implications differ for this group²⁷.

We found a small group of patients in a vegetative state among the nursing home population and from a point of view of efficiency of care it may seem that concentration of care in a limited number of specialised nursing homes is to be recommended. However, we would strongly advise against such a development. It is known from literature that the bond between the family and the patient remains strong.²⁸ This was something we also encountered in an earlier part of our study⁷ and care should include the fostering of this relationship and not frustrating it by referring patients in vegetative state to centres far away from their families. Provision of a central team of experts for questions and consultations with care providers may be an alternative to specialised centres.

The present study demonstrates that the dedicated care for patients in a vegetative state may last for years and years. It is clear that every single case in this twilight zone between life and death will have immense impact on the families, carers, and society, despite the small numbers.

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Chapter 7

Allowing a patient in a vegetative state to die
in hospital under the direction of a nursing
home physician

Published as: JCM Lavrijsen, JSG van den Bosch, H. Olthof, PPA Lenssen. Het laten sterven van een patiënt in een vegetatieve toestand in het ziekenhuis met de verpleeghuisarts als hoofdbehandelaar. *Ned Tijdschr Geneeskd* 2005;149:947-50

Doen of niet doen; daar gaat het om

To do or not to do, that is the question

Allowing a patient in a vegetative state to die in hospital under the direction of a nursing home physician

Introduction

Since the eighties of the last century, this magazine has periodically focussed attention on the fate of patients who have never regained consciousness following an acute brain incident. The contributions mainly concerned the clinical features, the diagnostics, prognosis, treatment, ethical dilemmas and a description of withdrawing medical treatment in practice^{1 7}

The patients described were all in a vegetative state: they breathe independently, they show a sleep-wake cycle, but no signs of consciousness, they are “awake but not aware”⁸. There is an increasingly broader consensus regarding the acceptability of withdrawing futile medical treatment with respect to these patients when the prognosis has become hopeless^{9 11}. Such is the case after a period of 3 to 6 months if the condition has a non-traumatic cause, or after one year following a trauma^{9 12}. It is the responsibility of the physician to ensure that the family receives adequate counselling in order to discontinue the treatment at the right time^{10 13}

However, this proves to be difficult in practice. In the unstable, acute phase in hospital, during which the patient is dependent upon medical technology, the prognosis is often not clear enough to justify withdrawing treatment. Studies indicate that the family renews the bond with their loved one in the stable, late phase in which recovery is no longer expected, after which it is difficult to still withdraw the treatment despite the hopelessness of the situation¹⁴

These insights have taught us to draw up a multidisciplinary treatment plan, in which the family is expressly involved, as soon as possible after a vegetative state has occurred. The plan provides a sketch of the scenario for the policy that is to be pursued for *this* patient with a view to allowing for every chance of recovery, but at the same time preventing the hopeless continuing of a vegetative state, a fate that is often described as ‘worse than death’¹⁵

If it is obviously too soon to make a definitive decision in the hospital and possibly too late in the nursing home, then the nursing home physician can contribute by taking over the responsibility for the treatment in hospital following the acute phase. The National Health Council refers to this phase in the treatment of a vegetative state as the ‘waiting phase’⁹. Transferring the treatment in this phase is in keeping with the trend of increasing co-operation and the transmuralisation of care¹⁶

The case history below is an example of a situation of this kind

Case history

One morning, a bicyclist finds a 52-year-old jogger unconscious and looking blue. He rushes to the nearby hospital on the assumption that he will find an ambulance there. This proved to be a miscalculation and the patient is meanwhile discovered a second time by a walker who alerts a local resident. The latter calls an ambulance and positions the patient in a recovery position. Attempts to resuscitate the patient were not made until the ambulance arrived. Upon arriving at the hospital, the cardiologist determines ventricle fibrillation together with an antero-lateral myocardial infarction, for which reason a primary PTCA was carried out in a nearby hospital. The patient's heart stabilises, but he is in a deep coma (Glasgow Coma Scale of E1M1V1).

He receives artificial respiration during the first eight days and an endotracheal tube is placed. On the seventh day, the patient opens his eyes every once in a while and the functioning of the brainstem proves to be restored in such a way that the patient can breathe independently. However, he shows no sign of consciousness and a vegetative state is established. Intercurrent infections are treated. He is moved back to the cardiology ward of the local hospital fourteen days later.

As the patient is cardiologically stable and the validity determining features are neurological, this brings about a discussion regarding who should be the physician who is responsible for the total treatment. Thirteen specialists have been involved in his treatment by the time he is transferred to the Neurology ward: the intensive care physician, cardiologist, neurologist and Ear-Nose-Throat (ENT)-specialist of the associate hospital, the cardiologist and neurologist of the patient's own hospital, as well as the lung specialist for the purpose of treating various bronchi infections, the internist due to a deranged diabetes, the urologist for the purpose of inserting a suprapubic catheter and the treatment of urinary tract infections, the ENT-specialist for the removal of the endotracheal tube, the surgeon for the treatment of a head wound and the insertion of a PEG catheter in cooperation with the gastroenterologist, the dermatologist due to a mycosis, and the rehabilitation specialist for recommendations concerning the subsequent phase. The latter recommends that the patient be admitted to a nursing home in view of his vegetative state.

The hospital has a transfer unit where the nursing home physician is responsible for the treatment. He is also available as a consultant, but a consultation isn't requested until after a few weeks due to intercurrent disorders. The neuropsychologist has meanwhile been called

in as well for the purpose of starting a stimulation programme together with the physiotherapist and speech therapist. This is tolerated by the neurologist, as there are no other possibilities for therapy. However, a clear treatment plan is lacking. The family brings in an acupuncturist who believes that he can contribute to the recovery of the patient.

Various specialists speak with the family at different moments in time, each from his/her own point of view. It is then in any event clear to the family that he is cardiologically stable, that the prognosis is pessimistic in a neurological sense and that the patient would therefore no longer be put on the respirator should there be a somatic cause to do so. The specialists repeatedly concluded that 'the wife is not yet ready to make a decision regarding non-treatment' (quotation from case file).

The nursing home physician performs the consultation ten weeks after the event and the diagnostic protocol as published in this journal is applied in the presence of the family.⁶ The patient is in a vegetative state with hyporesponsive characteristics.¹⁷ The recommendation to quickly transfer the patient to the transitional ward was in keeping with the needs of all those concerned. This was realised within the week and a start could be made with systematically formulating a treatment plan.

The first step involved once again discussing matters at length with the patient's wife. The starting point that solely the physician bears responsibility for decisions regarding medical proceedings – after having consulted with the family, of course – was explained at this time. That brought some relief, as the spouse had been asked, repeatedly since the event, to make choices concerning the medical proceedings.

She confided that she was afraid that she would lose her husband as a result of a myocardial infarction, as his entire family has some form of heart disease. His mother, brother and, recently, his sister had died following a heart infarct and his two remaining brothers had also experienced a heart infarct. He had refused preventive catheterisation for fear of the findings and consequences. The married couple has two children, ages 12 and 15, who find it hard to come to terms with the situation and who are still hopeful.

There is no knowledge of previous statements on the part of the patient concerning what should be done in a situation of this kind. He did, however, at some time remark "I'd sooner not end up like that" in reference to a demented family member in a nursing home.

The various phases in the course of a vegetative state were discussed with the family, as well as the withdrawal of treatment when appropriate. Going through all of the information was the first step in that respect. The stimulation programme was discontinued for the time being, as there was no response on the one hand, and to give the family a bit of peace on the

other It was agreed that complications would be treated, taking into account the proportionality, in the sense that there is to be a balance between the means used and the goal to be reached The family, paramedicals and the nursing staff agreed with this policy

After making an inventory of all of the information and opinions, the nursing home physician also attended a therapy session of the acupuncturist The acupuncturist was under the impression, as was the wife, that the patient was responding to the therapy It was found, however, upon observation that the acupuncturist was responding to the patient and not the other way round, thus suggesting an interaction When confronted with this, the family agreed to discontinue this activity as well

Six days after taking over the care of the patient and almost three months after the incident, the nursing home physician is called one Sunday afternoon because the patient's condition has suddenly deteriorated An examination showed a sepsis on the basis of an airway infection The nursing home physician in charge of the case is called in conformable to our internal agreement concerning the course of action that is to be followed once important decisions must be made regarding patients with this type of complex problems He confirms the diagnosis and both nursing home physicians are of the opinion that curative treatment is disproportional in this case in view of the critical condition of the patient, the unfavourable prognosis based on the knowledge at hand and the decision made before that the patient would no longer receive artificial respiration The nursing home physician in charge of the case takes over the responsibility from the physician in attendance

Following a thorough explanation, he confronts the wife with his proposal to pursue a symptomatic policy, in the course of which the patient is expected to die Although she and the other family members are taken by surprise by the rapidity of these developments, the wife – given the previous discussions – can agree with this policy in the knowledge that the responsibility for the decision lies with the physician The situation is discussed with all of the immediate family members and the children in particular are prepared for the approaching death of their father The patient receives oxygen, paracetamol, and morphine and midazolam to relieve the dyspnoea and motor agitation

The surroundings are rearranged in such a way that everyone can come and pay a farewell visit Hospital attributes, such as bed railings and handgrip, are removed and the oxygen supply can be discontinued later on as well, without the cyanosis returning Candlelight and music transform the atmosphere into an almost domestic situation There is no need for pastoral support The patient's condition deteriorates further in the course of the

evening and he dies peacefully in the presence of his wife and children shortly after midnight
His own nursing home physician has stayed until the end

Discussion

The case illustrates how nursing home medical expertise can be put to use in hospitals, precisely in the transitional stage between the acute treatment phase and the treatment and care in specialised care institutions. Whereas transmural care on the part of nursing homes with the emphasis on co-operation between the nursing home physician and the general practitioner has already been described in detail,¹⁸ transmural wards for patients who no longer require hospital care, but who are waiting for specialised care, are a new phenomenon in hospitals. In the past years, 46% of the Dutch hospitals have set up a transmural ward, the most important reason for which concerned improving the transfer rate of patients and the quality of care according to research by *Prismant*.¹⁹ In 92% of these wards, the medical responsibility lies with the nursing home physician. In 2003, there were 223 admissions to the transfer unit of the patient described, which has 20 beds, with an average waiting period of 8 days. The average waiting period on a national level is 11 days.¹⁹

In the evaluations with the medical specialists, paramedical and nursing staff and the family of the patient described above, there proved to be a need for multidisciplinary co-operation under the central direction of the nursing home physician, who could go beyond the other professionals and make decisions concerning the treatment as a whole using the medical information from the various specialist subsectors. All of the professionals, including the nursing staff, found the period prior to having the nursing home physician take over the treatment to be mainly characterised by a lack of direction and a vagueness in policy. This undesired and unintentional lack of clarity had its effects on the communication with the family, the non-specific acts on the part of the paramedicals and the unsupervised actions of the acupuncturist. Thanks to the systematic, generalist approach of the nursing home physician and clear communication with the family regarding this, it was possible to plot a clear line of treatment with which all of the professionals could agree. This integrated, problem-oriented, multidisciplinary method of working is a core competence of nursing home physicians, rendering them also suitable to act as the physician who is responsible for the treatment as a whole in a transmural setting.

(http://nvva.artsennet.nl/upload/113/26273/takenpakket_verpleeghuisarts_sociaal_geriater.pdf)²⁰

In the treatment of patients in a vegetative state, it appears that the waiting phase in the course is pre-eminently suitable for laying the foundation for co-operation where it concerns

far-reaching decisions. It is the phase in which the medical situation stabilises, the prognosis changes from hope to hopeless and the family is able to let go, however difficult that may be. The wife of the patient later looked back on the course of events with approval particularly where it concerned the manner in which the nursing home physician assumed the responsibility for the entire direction and decision-making process. This is conformable to our basic principle that the physician is to decide *after* consulting instead of *in* consultation with the family. Due to the systematic approach, she felt confident at the time of the crisis that the right thing would be done. The fact that the physician was present until the end confirmed this final responsibility for the course of events.

A good relationship with the family could be developed in a brief, intensive period under the clear direction of the nursing home physician, which, in combination with the hopeless prognosis, would have been the basis for discontinuing the treatment of this patient even without this complication. After all, in the case of a vegetative residual state following an *unwitnessed cardiac arrest*, it could be claimed that the *resuscitation* (in Dutch 're-animatie') as a form of treatment in the literal sense of the word – namely restoring to consciousness – has failed.

Conclusion

By means of consultation and by taking over (the responsibility for) the patient in a transfer unit, it is possible to quickly utilise the expertise of nursing home physicians, precisely during the waiting phase in the treatment of a vegetative state, in order to contribute to transmural co-operation so as to do that which is useful and to prevent that which is hopeless. The concept of 'intensive care' also applies to '*not doing*' in this respect, though that is less spectacular to the outside world compared to '*doing*'.

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Chapter 8

Main conclusions and general discussion

Main conclusions and general discussion

This chapter presents the most important conclusions that could be drawn from the study as a whole and places the findings in a broader context by means of a general discussion. From this, recommendations are given for in practice, education and policy. The chapter is concluded with recommendations for follow-up studies and an epilogue.

Main conclusions

It has been recognised to date that there is scarcely any knowledge of the long-term course and care for patients in a vegetative state¹⁻³. The study as described in this thesis sheds light on this long-term course and care, which can be summarised as follows.

The long-term care and treatment of the patient in a vegetative state is complex and intensive, involving a considerable use of medication and degree of co-morbidity, sometimes of an extraordinary and as yet unknown nature, such as keratitis filamentosa. Various disciplines and medical specialists were involved in the long-term treatment and the family received intensive guidance in “growing” towards key decisions. The attitude of the physicians changed in the course of time from a reactive approach to a more proactive approach, in which an evaluation of the treatment as a whole, including tube feeding, became the starting point in preventing a hopeless vegetative state. The first experiences in practice show that the patient can die a dignified death after withdrawing the treatment. The attitude of the family is found in this study to be a crucial factor in the ultimate decision of the physician concerning treatment, even if it was made clear to the family beforehand that the responsibility for the decision lies with the physician instead of with the family. It ultimately became apparent that the nursing home in this study had no standard solution to alleviating the fate of the patient and the family. Each case was considered individually, in which the physicians looked for the best solution to each situation.

There are indications in the study that the ‘waiting phase’, as it is referred to by the Health Council, following the acute phase is possibly crucial where it concerns decisions to prevent a hopeless vegetative state. Promptly after the acute phase, nursing home physicians can act as the physician with the responsibility for the treatment as a whole in the so-called ‘transfer units’ in the hospital. In their central, problem-oriented central direction, they can initiate a multidisciplinary treatment plan with ample attention for centrally co-ordinated

communications regarding the goals of the treatment and the key decisions in the long term. This is in keeping with the transmural co-operation between hospitals and nursing homes.

A diagnostic concept was developed as a basis for medical treatment on the borderline between life and death. It recommends the use of unequivocal terminology and provides answers to the questions how, by whom and at which time the diagnosis of a vegetative state can be made.

Using that concept as a uniform basis, a prevalence study was conducted in which it was found that, of the 32 nursing home patients who were in a vegetative state in September of 2003, 26 no longer have any prospect of recovering; a substantial number of these patients has meanwhile survived in a vegetative state for longer than 5 years. Four patients had been under observation for too short a time at the time of the study to make any definitive statement concerning the prognosis and recovery, if any. It was found on the basis of the data concerning the end of the treatment in the period January 2000-September 2003 that the low prevalence by comparison with literature data cannot be explained by the systematic withdrawal of artificial nutrition and hydration. It appears that most of the patients in a vegetative state die as a result of complications that, in a majority of the cases, are not treated within the scope of a non-treatment policy.

General discussion

In addition to the separate discussions in the various chapters of this thesis, this paragraph places a few conclusions in a broader context and explains them in more detail. The significance of this study in particular is examined against the background of the most important discussions of the past decades concerning the question of whether or not tube feeding, as a form of medical treatment, may be withdrawn and who is to make this decision.

The withdrawal of medical treatment, including tube feeding, may be an acceptable scenario for letting the patient die

The first description of this scenario is given in chapter 2. In that situation, it was ultimately concluded that continuing the medical treatment no longer contributed to the well-being of the patient, after which the treatment, including tube feeding, was discontinued and the patient died peacefully.⁴ Although no jurisprudence was as yet available on this subject at the time of

the decision-making, providing artificial nutrition and hydration was considered medical treatment and was therefore evaluated as such. As explained in the introduction, the foundation for this approach was laid in 1985 by means of a publication by Leenen.⁵ He described that, in this context, providing artificial nutrition and hydration can 'be made medical' so much that it is taken out of the standard normative framework and can be considered medical treatment and evaluated as such. According to Leenen, the fact that ending the artificial nutrition and hydration involves setting in or continuing the process of dying still does not render the action euthanasia. He deems the medical treatment in this context to be entirely based on medical criteria. And because of the medical nature of the judgement, it does not fall to the family of the patient and he indicates that 'apart from that, family members cannot make decisions concerning their relative'.⁵ At the time, Leenen did comment that the withdrawal of artificial nutrition and hydration should lead to the patient's death within the foreseeable future, because no longer providing nutrition and hydration would otherwise result in a form of 'starvation and dehydration' that is not acceptable.

The case in chapter 2 shows the fear of the last mentioned to be unfounded in this context. This observation comprised an important message for medical practice: it was shown that it was acceptable to withdraw artificial nutrition and hydration and that this led to a dignified dying process. It was important to set this experience, in relation with the theoretical assumption that patients in a vegetative state are not capable of suffering, against the representation in the lay press.⁶ Afterwards, the case was subjected to a judicial investigation and it was concluded the physician had approached the case 'with due care, in both a medical and ethical sense' and so legal proceedings were not instigated. From this it was deduced that a decision-making of that kind should be made on medical grounds.⁷ With the permission of the family, the messages of the clinical lesson were then introduced in the public debate.^{8,9}

At the time, the clinical lesson gave cause for letters to the editor of the *Nederlandsche Tijdschrift voor Geneeskunde* concerning how easy it is to insert a PEG-tube, the difference between the scenario as presented and the active, unsolicited termination of life, and how the family is prepared *prior to* the admission of the patient to the nursing home.^{10,12} All those who responded approved of the policy as pursued. Upon replying to the letters, the opportunity presented itself to explain and supplement, within the framework of the conclusion of this chapter, a few issues that arose from the article.

In the first place, this concerns the importance of adequately formulating the medical grounds for a life-prolonging intervention, such as the insertion of a PEG-tube.¹³ The fact that this operation has become much easier in a technical sense since the 80s was not considered

relevant as long as there are no sound (medical) grounds for it in relation to the goal of the treatment. Subsequent publications also warned against the casual use of the PEG-tube for the sake of convenience, which was later sometimes referred to as a ‘trap with no escape’ in hopeless situations.¹⁴ As early as 1989, the jurist Sutorius wondered if the physician was even lawfully authorised to continue the treatment in such cases if the patient’s consent and a concrete goal in terms of treatment are lacking.¹⁵

The second elucidation upon responding to the letters concerned the sharp distinction that we draw between the withdrawal of futile medical treatment and actively ending a life without a request.¹³ There was no cause for the latter scenario, as the course in the terminal phase of the patient concerned passed off calmly. The fact that it is assumed that these patients do not suffer is no foundation for the administration of ‘euthanatics’, which has been mentioned by the Committee on the Acceptability of the termination of Life (CAL) of the Royal Dutch Medical Association (KNMG) as a possible scenario.¹⁶ This also does not apply because there is no request on the part of the patient. In 1992, this proposition was incorporated in a critical comment on an earlier CAL-memorandum of the KNMG.¹⁷ In addition to the criticism regarding the term ‘termination of life’ in this context, the comment also explained that there is no ‘slippery slope’ in the application of scenarios for a dignified death for patients in a vegetative state, as some fear. After all, there is still the distinction between the withdrawal of futile medical treatment (letting the patient die) and actively terminating the patient’s life with ‘euthanatics’ (making the patient die). This distinction was also explained at the request of the *Nederlands Artsenverbond* in its journal *Vita Humana*.¹⁸ Here, grounds were given for the proposition that, in addition to moral objections, there are also insufficient medical reasons with which to justify the administration of ‘euthanatics’. There are no indications in the prevalence study that this practice is applied in nursing homes (chapter 6).

Following the – in terms of decision-making – crucial year of 1989, it also became clear that the withdrawal of medical treatment, including tube feeding, was being incorporated in policy-related memorandums from professional groups. As from that year, the first international publications appeared from professional groups concerning the vision on the acceptability of withdrawing artificial nutrition and hydration as a form of medical treatment from patients in a hopeless vegetative state.^{19, 21}

In the Netherlands, the lesson as described in chapter 2 of this thesis was included in a number of specific publications on this subject, such as a thesis by Pranger in 1992, the report from the Health Council in 1994 and that of the Committee on the Acceptability of the

termination of Life (CAL/KNMG) in 1997.^{16 22 23} The practical experience as described was significant in these publications in order to substantiate the conclusion that the patient can die in a dignified fashion following the discontinuation of tube feeding. This was found to have been considered in the assessment of the acceptability of this scenario.

It is evident from the various requests for advice and consultations that, since then, the scenario of withdrawing the treatment as described in chapter 2 was applied elsewhere as well. It is also evident from recent treatment data concerning the period 2000 through September 2003 (chapter 6) that this scenario has been put into practice in other nursing homes as well. And with that, the case in chapter 2 appears to have created a bridge at the right time between theoretical concepts regarding the acceptability of discontinuing tube feeding and a workable application of this concept in practice. It was found, however, during the conference *Life-sustaining treatments and vegetative state: scientific advances and ethical dilemmas* in the Vatican City (www.vegetativestate.org) that the bridge has not been realised everywhere in the year 2004. In view of the discussions that it raised, it was obvious at the conference that the case in chapter 2, although published 14 years ago, is still not outdated. It became clear during the conference that, on an international level, there is presently still no universal consensus on the acceptability of withdrawing tube feeding as a form of medical treatment from patients in a vegetative state. The implications of the statements by Pope John Paul II at the conference – tube feeding as *ordinary care* and the withdrawal of this care as *euthanasia by omission* - cannot as yet be surveyable and are the subject of debate.^{24 25}

There is no standard solution to alleviate the fate of patients in a vegetative state and their families.

This conclusion can be substantiated by the results as described in the prevalence study in chapter 6 and by means of the various scenarios in the case studies.

This conclusion is in keeping with the results of studies in the 90s into the attitude of physicians towards the acceptability of withdrawing tube feeding as a form of medical treatment from patients in a vegetative state. Although physicians give preference to not treating complications, a majority of physicians, particularly in Western countries, proved to consider it ethically acceptable to discontinue artificial nutrition and hydration in this target group.²⁶⁻²⁹

The *case studies* as described in chapter 3 of this thesis show that, despite the increasingly broader consensus among physicians regarding the futility of continuing treatment, the withdrawal of tube feeding as medical treatment was not realised in all of the cases. This shows that this scenario is not a standard solution in practice, but that the physicians look for the best solutions for each individual patient with their families. The significance of this study for the opponents of the scenarios in which treatment, including tube feeding, is withdrawn is perhaps that it is now clear that the scenario that they fear is not used as a panacea in situations of this kind, nor is this the case in situations in which physicians present the possibility. These experiences are confirmed by the results of the prevalence study, from which it was found that there is no systematic withdrawal of tube feeding from these patients in the Dutch nursing homes. The *case studies* also show that the proposition of the CAL-committee of the KNMG – namely that the physician is to convince the family of the futility of the treatment – cannot always be realised in practice, particularly where it concerns accepting and implementing the consequences.¹⁶ The essence of that dilemma is perhaps best phrased in the quoted statement of a family member ‘*This is a fate worse than death, but we don’t want to lose him*’ (chapter 3, table 2)

The conclusion that there is no standard scenario in situations of this kind is also in keeping with the vision of the jurist Sutorius on *bound value judgements* as published in 1989.¹⁵ Upon assessing the well-being of the patient, for the benefit of which medical treatment should be provided, he argued in favour of distinguishing between the *free value judgements* of the physician and the *bound value judgements*, bound by the individual situation of the patient and by the profession, being the objectives of medical science. In the opinion of Sutorius, the physician should abstract from any general or personal value judgements in his professional capacity, whereas bound value judgements may play a role. The *case studies* illustrate how the decision-making is linked to the individual situation of the patient and the family in each case. The link with professional standards has already been pointed out above.

As the attitude of the physicians became increasingly proactive, the attitude of the family became a crucial factor in the ultimate decision-making in the nursing home

This conclusion follows from the *case studies* as described in chapter 3. This is an initial description of the changed attitude on the part of nursing home physicians in the course of

time and their decision-making. Starting from these descriptions, the proactive attitude of the nursing home physicians can first of all be explained by the increasing experience with patients in a vegetative state and their families. This is evident in the case studies from the fact that the learning points from each individual case are put into practice in each subsequent case.

The development of the field of nursing home medicine as mentioned in the introduction may have contributed to this development as well, seeing that the problem-oriented cyclic work methodology and goal-oriented central direction constitute the pillars.^{30 31} The proactive method of working on the part of nursing home physicians in the decision-making was also described in a recent study outside of the context of the vegetative patient, namely the decision-making process in relation to forgoing artificial nutrition and hydration in nursing home patients with dementia.³² It was also clear from this study that the families hold different views regarding whether or not life-prolonging procedures should be carried out and that nursing home physicians find it important to reach a consensus with all of the parties concerned.

Concerning the withdrawal of tube feeding from patients in a vegetative state, it is evident from this thesis that a consensus with the family is not always reached, despite the proactive attitude. This is in keeping with the scarce descriptions in the literature, from which it is apparent that the families of the patients in a vegetative state mainly resist the scenario in which tube feeding is withdrawn.³³⁻³⁵

Although this thesis does not concern a specific study into the perception of family members, a few factors that may explain this resistance and, where possible, prevent or diminish it can be pointed out on the basis of the findings. This is relevant, as the attitude of the family is important in the ultimate decision-making of the nursing home physician.

Establishing the correct diagnosis is first and foremost of importance, together with adequately informing the family on the medical facts of the situation. The diagnostic concept in chapter 5, in which the participation of the family is included, may prove helpful in that respect. The distinction between a vegetative state and a *Minimally Conscious State* in particular is crucial, as the manner in which the consequences of withdrawing medical treatment are perceived may differ depending upon whether or not a degree of consciousness is presumed.³⁶ However, studies show a majority of the family members of patients in a vegetative state to presume that their relative is conscious to some degree.^{34 35}

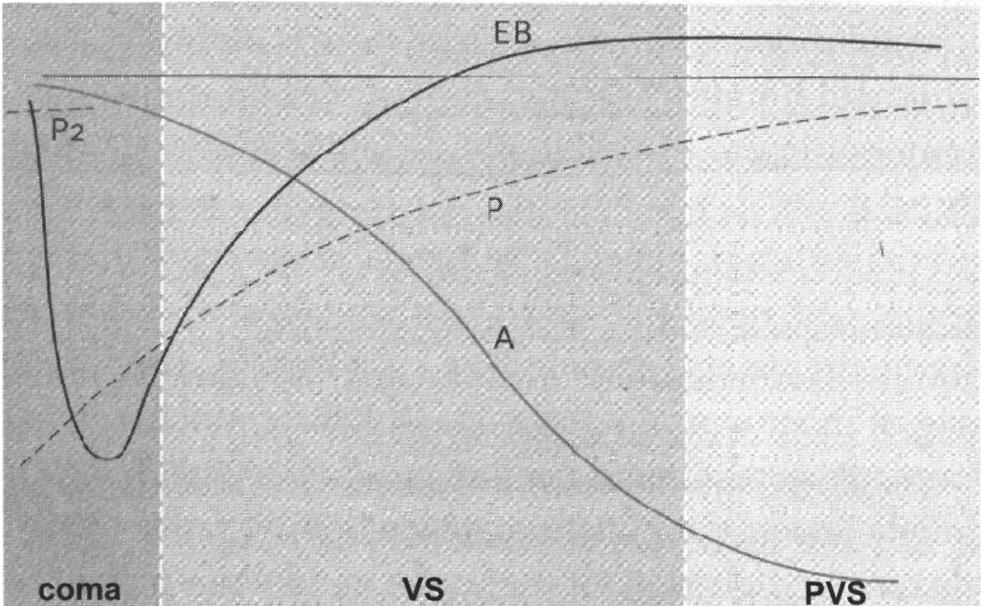
The prevalence study as described in chapter 6 shows some indication that this presumption is not always wrong, particularly with regard to the group of 8 patients that could be distinguished from those in a vegetative state. According to the classification of the *International Working Party on the Management of the Vegetative State* in 1996, these patients were in a 'transitional/borderline state'¹. These patients can react emotionally to family members and this may have huge implications for the idea on the part of the family that 'the person is really there' and for the family's view regarding whether or not tube feeding is to be withdrawn³⁶. The conceptual confusion regarding definitions and diagnostics that lasted until the 90s (chapter 5) and the fact that several patients have been in a vegetative state for a prolonged period of time (chapter 6) emphasises the importance of the combination of adequate diagnostic procedures and proper counselling of the family.

Another factor that may contribute to the aversion towards the withdrawal of treatment is the problem of letting go of the patient in the stabilised long-term phase, particularly if a new balance in the situation has been achieved (chapter 3). It may be enlightening, for an understanding of the processes that may influence the decision-making in the treatment process of patients in a vegetative state as a whole, to relate this study to a previously published graphical concept by Minderhoud³⁷. Using a diagram (figure 1), he described the following processes as decisive factors for a policy in relation to the space of time: the emotional bonding of the family to the patient, the knowledge concerning the prognosis and the dependency of the patient on the treatment.

In the acute phase, when the family has been prepared for the worst and the patient is highly dependent upon the treatment, uncertainty concerning the prognosis can stand in the way of the decision-making regarding the withdrawal of treatment. The *case studies* in chapter 3 illustrate his proposition that it is precisely the other factors that may interfere with an intervention in a later phase, when there is more clarity regarding the bleak prognosis. After all, the bond with the patient is strong in that phase and the patient is less dependent of drastic forms of medical treatment. The case in chapter 7 indicates that precisely the phase between the acute phase in which there is still hope and the long-term phase in which there is no hope, which is referred to as the 'waiting phase' by the Health Council,²³ may be crucial for interventions to prevent a hopeless vegetative state. It is precisely in this phase that the bond with the patient once again strengthens, whereas the prognosis changes from hope to hopeless. The medical dependency of the patient decreases during those months, although there are still complications on a regular basis, as is shown in this study as well. It appears to

be worthwhile to make full use of this phase in practice in order to lay a foundation for decision-making regarding the withdrawal of futile medical treatment.

Figure 1 (borrowed with permission)



Theoretical curves representing the degree of dependency (A) of the patient in a coma and in a vegetative state (VS) upon the treatment in order to stay alive, the degree to which there is clarity regarding the prognosis after the accident (P) or following the occurrence of complications later on (P2), and the strength of the emotional bond (EB) that the family and, possibly, professional staff experiences with the patient.

The case of the patient in the transfer unit of the hospital (chapter 7) shows that a hopeless vegetative state could be prevented in that phase with a proactive approach and intensive guidance in a short period of time. The input of knowledge regarding the long-term course and the counselling of the family on this were important in that respect. The findings in this thesis enable the caregivers and the families to form a picture at this early stage of what may happen after the hospital phase and which dilemmas may arise. It is furthermore possible to align the wants, expectations and possibilities regarding the various scenarios for the long term even before the patient is admitted to the nursing home. The value of this has already

been emphasised in a response to the clinical lesson in chapter 2.^{12 38} It was also expressed there that discussing the starting points prior to the admission was sooner seen as an intention to ‘embark upon the road ahead together’, rather than reaching an agreement concerning the end of the treatment beforehand.³⁸

Finally, one’s view of whether or not the patient will suffer after the discontinuation of artificial nutrition and hydration may contribute to the resistance towards that scenario. In addition to explaining the theoretical assumption that patients in a vegetative state are not capable of suffering, the clinical lesson in chapter 2 was found to be useful in practice in counselling the families on the scenario of the discontinuation of tube feeding and the consequences for the patient. On one occasion, the family of the patient concerned passed this information along to someone in the same situation (chapter 3). This is certainly advisable if the family’s objections to a certain scenario are mainly determined by misconceptions on the basis of sources other than scientific. Although further studies are required to supplement the practical experience, a similar positive experience with the withdrawal of tube feeding has meanwhile been put forward at the above mentioned conference in the Vatican City by a family member of a patient who had been in a vegetative state for a period of 23 years.³⁹

Our study shows that, despite a proactive approach, there may still remain a difference of views between the physicians and the family regarding the withdrawal of the treatment. That is the fact that remains at the end of this study and that will be further explored in subsequent studies. Describing and publishing the dilemmas abroad may perhaps contribute to the learning processes elsewhere, so that not every culture is forced to experience its own ‘Stinissen’ or ‘Schiavo’ case.

Methodological considerations

Different methods were used in this thesis, depending on the research question. A clinical dilemma did lead directly to the first qualitative, descriptive case study (chapter 2) and this resulted in a more detailed qualitative study regarding patients in similar situations (chapter 3). The latter then led to two specific qualitative descriptive studies: one concerning a remarkable co-morbidity (chapter 4) and one concerning an early intervention strategy in hospital (chapter 7). Because of the lack of a ‘golden standard’ for diagnosing a vegetative state, as is evident from the international discussions on this theme, a practical, diagnostic

guideline was developed on the basis of a literature search and an expert meeting (chapter 5). This was the basis of the quantitative part of this thesis, the prevalence study (chapter 6).

The methodological choices in this thesis must be seen against the background of a research area that had not been explored before: the long-term care of patients in a vegetative state. Initially, information from daily practice made us assume that it only concerned a small group of patients. Apart from the prevalence study, the focus of this thesis is on qualitative studies and serves as a first step to illustrate and understand the problems of the long-term care of patients in a vegetative state. This is the particular strength of qualitative research, which is appropriate in areas that have received little previous investigation. It can lead to the development of concepts that help us to understand phenomena in natural settings, giving due emphasis to the meanings, experiences, and views of the participants.⁴⁰ Moreover, decisions, particularly in the long-term care of patients in a vegetative state, are qualitative rather than quantitative in nature.

Case studies were chosen as a method to describe the themes in long-term care in the way that they are integrated in their natural context of daily practise. Case study evaluations are valuable where broad, complex questions have to be addressed in complex circumstances, particularly where those questions are concerned with how or why events take a particular course.⁴¹ This choice has advantages and limitations. The main advantage is that by describing a limited number of patients in this way, integrated processes of decision-making and communication can be thoroughly illustrated against the background of the clinical course and the individual patient's social and family setting. The narrative elements in the descriptions can eloquently express in all its details 'the story of the patient' and contribute to the insight into the dilemmas in practice at different times. Among the classical examples of this approach is the in-depth description of the individual's medical life history and its interaction with the family members, by Huygen.⁴² This formed the basis of later quantitative studies of the long-term outcome of illness and disease in general practice. Case studies also have limitations. For example, there is the question of the extent to which one can generalise the results as reported, especially with regard to the case studies in different wards of one nursing home. However, the primary goal of these first case studies was not the generalisability, but rather gaining in-depth information of the long-term course of patients in a vegetative state. We think the description of the different treatment scenario's and weighing in this defined population show a representative picture of the possible clinical courses and dilemmas. The results of the prevalence study in all Dutch nursing homes confirmed that all treatment scenarios's described in the qualitative study were applied. Therefore, we think the

setting that underlay the case studies by and large resembled Dutch nursing homes. The conclusions on the development in clinical decision-making for patients in a vegetative state over time relates directly to the context described, but, based on the observations above, will be relevant for other nursing home physicians. It can be inferred from the prevalence study that so few patients with vegetative state are admitted, that it will only be possible in a few nursing homes to develop over time and over subsequent cases the experience, that has been studied in this thesis.

However, reservations should be made in generalising the results to other countries. Differences in health care, culture and legislation will influence the decision-making process, particularly in the context of the treatment of patients in a vegetative state. Moreover, the medical care for nursing home patients is different in other countries. In the Netherlands, the multidisciplinary care in nursing homes is directed by nursing home physicians who have followed a two-year specialist training programme⁴³. The long-term care of patients in a vegetative state is part of the education programme⁴⁴. However, despite the different organisation and education of the medical professionals, the experience described here may be recognised by physicians in other countries who bear responsibility in the long-term care of these patients.

Another limitation can be related to the choice of publishing the case studies in article form in bio-medical journals. As a consequence of the traditions of these journals, only limited text could be published and this was a limiting factor of this thesis. Qualitative research usually requires more words than quantitative research, as ‘words’ are the data of the study. This goes contrary to the traditions in biomedical publishing. The review process of the journals also forced us to reduce the information that was published. Yet, we are confident that it has been possible to pay tribute to the research data and meet the publication requirements at the same time. As a consequence, the descriptions represented the reality according to the research philosophy of “subtle realism”, an attempt to represent that reality rather than to attain “the truth”⁴⁵.

This research project has laid a basis for further investigations into the themes of this thesis, in which the complementary relation between quantitative and qualitative methods can be fruitful. The themes highlighted by the case studies will be useful to generate specific data from the total population, which makes quantitative analysis possible. For example, the qualitative work of the filamentary keratitis can be seen as preliminary to quantitative research into the prevalence or the incidence. On the other hand, the quantitative work in the

prevalence study can be followed by qualitative research into specific themes, such as backgrounds of treatment decisions or the views of participants. Moreover, this can contribute to the validation process by using more methods and comparing results for convergence (triangulation) ^{40 45}

Recommendations for practice and education

For practice

Based on the focus of the long-term care in this thesis, I recommend the following approach for practice in addition to the recommendations in the different chapters

- In all treatment phases of a vegetative state, physicians should use *all the evidence there is* to establish an adequate diagnosis and prognosis as a basis of treatment- and care plans. For diagnosing a vegetative state the use of the multidisciplinary approach described in chapter 5 can be useful for diagnosing a vegetative state.
- In all treatment phases of a vegetative state, physicians should formulate the prevention of a permanent vegetative state as a collective point of departure. This implicates an attitude of a *shared responsibility* instead of a *transferable responsibility*.
- It should be explained to the families of patients in a vegetative state that recovery of consciousness and prevention of a permanent vegetative state are the goals of treatment.
- In every treatment phase of patients in a vegetative state, a multidisciplinary treatment- and care plan is necessary in which the overall goal of the treatment is formulated and in which contributions of other disciplines are directed in accordance with this goal.
- Regular evaluations of the overall treatment according to the recommendations in chapter 5 are necessary against the background of the diagnosis and changing prognosis, the results of these evaluations and its implications for the treatment- and care plans should be communicated with the patients' family.
- It is advisable that physicians communicate to the families that all forms of medical treatment, including artificial nutrition and hydration, can be considered as a 'trial treatment' to achieve the goal of recovery. Moments of evaluation are to be announced and those concerned can anticipate in the communications the point in time in the

future when all forms of medical treatment would be withdrawn as the chance of recovery is negligible

- It is advisable that physicians of long-term care facilities be involved in the care plans in 'the waiting phase' in hospitals, before patients in a vegetative state are admitted to these facilities. In this consultation, the different treatment scenarios in the long-term phase can be explained and the expectations of families can be discussed against the possibilities and points of departure of the long-term care facility
- It is advisable that physicians in the acute care mention the diagnosis vegetative state, the goals of treatment and the communication with the family about these goals in the referral letter to long-term care facilities
- Because few nursing home physicians can gain experience with this population, a national expert team for questions and consultations is recommended

For education

It is partly on the basis of this study that an educational programme has been developed for nursing home physicians in training. The programme consists of a knowledge quiz, preparatory assignments, video presentations and a literature document, in addition to the introduction and objectives. The 21-page literature document goes through the essences for nursing home physicians in training on the basis of more than 80 literature references⁴⁴. This literature document was periodically brought up-to-date as a result of this study. A historical context of the medical-ethical dilemmas in practice is provided in a video montage of various TV-fragments in which physicians, caregivers, family members, ethicists and jurists discuss the theme. In addition to the diagnostics pertaining to a vegetative state, the programme also focuses on discussing the dilemmas in practice on the basis of learning questions and case histories that are put forward. The educational programme aims at offering the frameworks with which to make one's own considerations on meaningful and futile medical treatment for patients in a vegetative state.

Apart from this category of patients, the programme also has a broader objective of reflecting upon medical treatment, in which the learning points from the method of working and the decision-making can be considered in other complex decision-making processes relating to patients who are unable to give informed consent. The programme therefore links up with other educational programmes regarding 'Ethics' and 'Medical end-of-life decisions'.

There is so much material present that each educational programme is to be adapted to the learning questions in the study group. The next step will involve offering this programme on

various levels, in which registration on the basis of learning needs is being considered. A possibility here is to distinguish between target groups without experience, with an emphasis on general aspects, diagnostics and video material, and target groups with experience, with the emphasis on discussing complex case histories.

This set-up can also be used for the development of training programmes for treatment teams. Some experience has already been gained in that respect in co-operation with an ethicist.

Recommendations for future research

As mentioned before, this study has laid the foundation for subsequent studies in a defined population that is limited in size. The following subsequent studies can be recommended:

- The recurrence of the prevalence study in the future in order to obtain clarity concerning developments in the prevalence and the factors that may be decisive in that respect.
- A study among the family members of patients in a vegetative state into the manner in which their attitude towards the treatment and coping has developed during the various phases in the treatment of the vegetative state and which factors are of influence in this respect. The object of this study is to develop knowledge of the as yet virtually unexplored area of coping problems with regard to family members and how this affects the policy that is pursued.
- A qualitative study pertaining to the family members, caregivers and physicians of the 9 patients in a vegetative state for whom the tube feeding was withdrawn in the period 2000-2003. This study may clarify how the terminal phase was experienced from various points of view following the withdrawal of the treatment. In addition, there is the possibility of a further study of the decision-making with respect to the factors that led to the withdrawal of the treatment.
- A prospective study into the long-term course, including decisive factors in the scenarios for treatment. The cohort as found could serve as a basis in that respect and the study could clarify whether or not the patterns in the scenarios and the course as found also apply in a larger group of nursing home patients.
- A prevalence study into *filamentary keratitis* in patients in a vegetative state. This study could confirm the hypothesis that *filamentary keratitis* is related to the long-term course of a vegetative state.

- Starting from the prevalence study to *filamentary keratitis* intervention studies to the various treatment methods This may produce an explanation of the mechanisms of the occurrence and treatment, which could contribute to an effective detection and treatment of the disorder It can be confirmed whether or not the simple intervention as presented in the current study (regularly opening the eyes) can surpass the commonly applied labour-intensive therapy of frequently administering medication
- More detailed *case reports* on specific or remarkable co-morbidity in the long-term course, such as fractures and spontaneous changes in hormone levels This detailed study can be used to explore the initial findings in this study in depth and can call attention to possible complications
- A transmural study into the decision-making, transfer and communication in the various phases of the treatment of the vegetative state The object of this study is to substantiate the importance of transmural co-operation in the treatment and communications, this on the basis of a joint responsibility to prevent a hopeless vegetative state
- An explorative, qualitative study into the moral dilemmas concerning patients in a vegetative state, in a situation in which no consensus has been reached between the physicians and the family concerning whether or not the treatment is to be continued The object of the study is to explore the possibilities of overcoming a deadlock

Recommendations for policy

In view of the limited group of patients in a vegetative state that was found in Dutch nursing homes and the finding on the basis of literature that the bond that the family experiences with the patient remains strong, it does not seem advisable to concentrate the long-term care in a few centres far away from the families

One could consider setting up a central team of experts for questions and consultations in practice A first step in that respect could be the development of transmural protocols on a national level regarding treatment with due care and communications in the entire course of the treatment of a vegetative state The systematic, multidisciplinary care plan system, as widely used in nursing home medicine and rehabilitation medicine in particular, can be used as a working methodology within that framework

The utilisation of the consultation function of nursing home physicians and the development of transfer units in hospitals is recommended to bridge the gap between the acute care and the long-term care in this context.

It is perhaps advisable in view of the limited expertise in our country to determine for each region the best care facilities for patients in a vegetative state in the neighbourhood.

It can be expected in the long term in view of the recommendations for practice within the scope of preventing a hopeless vegetative state, that an increasingly smaller number of patients in a vegetative state will require long-term care

Epilogue

This thesis developed from feelings of powerlessness regarding the long-term treatment of patients in a vegetative state. The results and the recommendations from this study may offer caregivers new possibilities of coping with this powerlessness. For the patients and families, however, the essence of the problems remains a human tragedy, in which the powerlessness will always persist, despite new medical, ethical or legal insights. This is an indication of the importance of a collective responsibility for the purpose of preventing this hopeless situation.

Being involved in this study goes hand in hand with reflecting upon medical proceedings in the context of the development of a vegetative state and whether or not one should let it continue. Providing insight into the dramatic side effects of advanced, medical technology can perhaps also promote the reflection upon medical treatment in general, in relation to the purposeful framework in which its origin can be found. It follows that those providing treatment have the responsibility to do what is meaningful and to prevent what is futile. But the (future) patients, as consumers of health care – at present often called clients by non-doctors – have also become a decisive factor due to the demands that are made concerning the use of current medical technology, even if the physicians do not see any benefit. This phenomenon was described in 1989 by Sutorius as *'het probleem van de tovenaarsleerling'* - *the problem of a sorcerer's apprentice*, who has got himself into quite a jam 'working magic' with a virtuoso technology, but who no longer knows how to go back or forth¹⁵

Hopefully, with the recommendations from this thesis, we will see less and less of a situation in which people find themselves in permanent circumstances that they do not wish upon themselves or others, and in which there seems to be no way back. We will have achieved a lot if the actions that are taken are not determined by a technological imperative, but rather by understanding that there is always the possibility of stopping something that is ultimately

found to be futile. That recognition would be a credit to medicine and contribute to its goal, namely not to cause harm: *primum est non nocere*.

I therefore end this thesis with the proposition that there is always a way back in the treatment of patients in a hopeless vegetative state, however difficult it may be to take that road: *'It's not too late to stop now'*.

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Summary

Summary

This thesis describes the problems of patients in a vegetative state from the following points of view: diagnosis, prevalence and the long-term course

The following research questions applied

- How, by whom and at which moment in time can the *diagnosis* vegetative state be made as accurately as possible?
- What is the *prevalence* in Dutch nursing homes with respect to patients in a vegetative state following acute brain damage and what are the characteristics of these patients?
- What is the *long-term course and care* for patients who have been admitted to a nursing home in a vegetative state following an acute brain disorder and who are not expected to recover anymore?

These questions are placed in a context in *chapter 1*, in which the reason for the study is explained from a historical, personal and professional perspective. This chapter also explains the structure of the thesis.

Chapter 2 provides a description of a situation in practice in the form of a clinical lesson. It concerns a 43-year-old woman in a vegetative state, in which complications with artificial nutrition and hydration by means of a nasogastric tube ultimately gave immediate cause for an evaluation of the medical treatment of the vegetative state as a whole. Whether or not to continue the artificial nutrition and hydration was also considered for the first time in this respect, even though no jurisprudence was as yet available on the subject. After carefully reviewing the decision-making, it was eventually decided not to have a PEG tube placed, even though the procedure to that end had become easier due to recent innovations in surgical technology. The patient died peacefully following the withdrawal of treatment.

The conclusion of the clinical lesson was that a permanent, hopeless vegetative state could be prevented through careful decision-making. This requires alertness regarding the critical moments in the decision-making and the view that the treatment is a process that should be totally evaluated on a regular basis. Intensive guidance of the family towards these key decisions is an important condition in this respect. The message of the case as presented was that withdrawing artificial nutrition and hydration could be considered as withdrawing futile medical treatment, if this treatment ultimately no longer contributes to the well-being of the

patient Another message was that, after discontinuing the tube feeding, the patient undergoes a dying process that is experienced by everyone as peaceful and dignified, which contrasts sharply with a few publications in the lay press at that time

And so in this case, the long-term course was mainly determined by the complications and the subsequent decisions of the responsible physician concerning the medical action to be taken, this after careful consideration on the part of others The results of this case gave reason to study the decision-making process and the long-term course for other patients in a similar condition

This took place by means of a qualitative, descriptive study in the form of *case studies*, which is described in *chapter 3* This is an initial description of 5 patients who were in a vegetative state lasting more than one year in a Dutch nursing home during the period 1978-2002 None of the patients described regained consciousness The general conclusion based on the course for these patients was that the long-term care and treatment is intensive and complex with considerable co-morbidity The clinical course depends upon this co-morbidity and the attitude of the physicians and the family towards the treatment in general, particularly whether or not complications are to be treated and whether or not the artificial nutrition and hydration is to be continued The attitude of the physicians changed from primarily reacting to complications, to a more proactive role in which an evaluation of the treatment as a whole, including tube feeding, has become the starting point This approach fits the development of nursing home medicine as a medical specialism, in which a problem-oriented, multidisciplinary method of working under the direction of the physician is followed, instead of the former reactive approach

The chronological order of the various cases offered possibilities of applying learning points from each previous case in each subsequent case The learning point in the first case (1978-1989) was that it is essential to regularly evaluate the medical treatment in its totality, rather than abstain from parts of the treatment In addition, withholding antibiotics for a urinary infection proved in this case not to result in an expected death within the foreseeable future, but rather in a chronically infectious condition with complications

The learning point involving the evaluation of the treatment of the vegetative state in its totality was applied in the second case, in which complications gave immediate cause to carry out this evaluation This case is worked out in detail in *chapter 2* and has already been described above This case raised the question of whether or not, apart from complications, a hopeless, vegetative state could be prevented with a total evaluation at an earlier stage

Following on from that, this proactive approach was chosen as the starting point in the third case as from the admission of a patient, in which it was made expressly clear to the relatives that the physician would be responsible for the decision-making and not the family. Following intensive guidance of the family with respect to 'growing towards' the physician's decision, the treatment, including artificial nutrition and hydration, was withdrawn after a period of one year and three months. This was the shortest course in these *case studies*.

This scenario subsequently proved not to be applicable to two other young patients, in which cases the parents gained a new balance in dealing with the situation. They did not accept the withholding or the withdrawal of the medical treatment. It was at the parents' express wishes that the treatment was continued, even though the physicians were of the opinion that continuing the treatment was futile for the patient. In one of these cases, the patient, despite being treated for pneumonia, died after having been in a vegetative state for almost 8½ years. There was no other solution as yet in the other situation but to continue the treatment following a vegetative state that had already lasted for more than 16 years.

This part of the study indicated that, nowadays, the decisive factors in the course are mainly the attitude of the family towards medical treatment in general, and whether or not the artificial nutrition and hydration is continued in particular. There was no standard scenario to alleviate the fate of these patients and their families, even though the physicians were increasingly convinced as time passed that the medical treatment no longer contributed to the well-being of the patient and that it had therefore become futile. The withdrawal of medical treatment in its entirety, including tube feeding, proved mainly to be acceptable to the partners of the two patients over 40 years of age, as being appropriate in view of the supposed wishes and values of their relative. Concerning the parents of 2 young patients who had achieved a new balance in dealing with the situation in the stable, long-term phase of the treatment, withdrawing the treatment was not acceptable, despite a proactive approach on the part of the physicians.

It became clear from the descriptions of the long-term course in chapter 3 that the treatment and care of patients in a permanent vegetative state is both intensive and complex, involving various disciplines and medical specialists. The patients showed considerable co-morbidity with complications, such as constipation, spasticity with contractures, regular infections of the airways, urinary tract and skin, mouth and dental problems and osteoporosis with the risk of fractures. It is evident from the course that infectious complications were not always lethal, even if they were not treated. And then there was also the risk of a chronic infection with complications, such as abscesses and fistulas in a terminal phase. An important learning point

from the *case studies* was that withholding from providing antibiotics to young, well-fed patients is not always an appropriate scenario for letting the patient die in a dignified fashion. Bedsores were observed as a complication only incidentally, and then particularly in the terminal phase. Remarkable findings were filamentary keratitis (described in chapter 4) and a spontaneous recovery of hormonal deficiencies after one year.

The filamentary keratitis is described in more detail in *chapter 4* as an ophthalmic complication in the long-term course. This disorder concerns a sort of inflammation of the cornea with ingrown blood vessels and the forming of filaments. The diagnosis was made by two eye ophthalmologists, independent from one another, with respect to two of the five patients in a vegetative state, as described in chapter 3. Because no clear relationship with a long-term course of a vegetative state could be found on the basis of the available literature, this phenomenon has been described in more detail in the form of two *case reports*. The description shows that this complication became a chronic problem in the long-term care of these two patients. It was initially supposed that the complication was caused by dry eyes as a result of insufficient blinking of the eyelids. The use of artificial tears, the recurrent treatment of infections with antibiotics/corticosteroids and removing the filaments mechanically for years and years did not, however, lead to a lengthy remission. The two patients experienced 36 and 24 episodes of a 'red eye' respectively, which in most cases were due to filamentary keratitis, varying in duration between 1 to 5½ months. The policy was changed after 15 years based on the theory that the filamentary keratitis could be brought about as a result of the too infrequent blinking of the eye regarding patients who more often close their eyes than keep them open. All eye medication was withheld for one of the patients and the family members and the nursing staff regularly opened the eyes. This resulted in the longest remission in the course of a vegetative state that had already lasted for more than 16 years. Up until the completion of this study in 2004 – a period of more than two years – there was no recurrence of the filamentary keratitis since the last exacerbation.

It was concluded that filamentary keratitis can be a chronic complication in the long-term course of a vegetative state with remissions and exacerbations. It is recommended to have patients with recurrent 'red eyes' referred to an ophthalmologist for the purpose of having a diagnosis made. In addition, those concerned are called on to report more findings of this kind and to conduct further study into an effective form of therapy.

Chapter 5 describes a diagnostic concept starting from current insights that can serve as a basis for medical treatment on the borderline between life and death. The concept provides an answer to the questions how, by whom and at which point in time can the diagnosis of a 'vegetative state' be made as accurately as possible, with the use of unequivocal terminology and criteria. This part of the study was realised on the basis of the results of a literature study and a debate on the subjects of discussion from that literature during a meeting of experts.

The term 'vegetative state' is considered most suitable for the condition that can be observed when patients open their eyes following a comatose phase, without regaining consciousness. It is concluded that the diagnostic criteria of the international study group *Multi Society Task Force on Persistent Vegetative State* are usable in practice in the Netherlands. The distinction between coma, *locked-in-syndrome* and a *Minimally Conscious State* is important in this respect. We propose a diagnostic assessment based on the *Glasgow Coma Scale* and with the systematic structure of a standardised research instrument (*Western Neuro Sensory Stimulation Profile*) that will be feasible and reproducible in clinical practice. The focus in this respect is a systematic, multidisciplinary, diagnostic method of working under the direction of a physician, in which other disciplines are to contribute, as well as the patient's family. This method of working is considered more important than the number of specialists involved, although it is essential that the responsible physician repeatedly verifies the diagnosis as made by the neurologist or neurosurgeon in the acute phase. It is recommended that the diagnosis be verified by an experienced and independent expert in the event of doubtful cases and *prior to* significant decisions concerning the treatment. It is considered important to repeat the clinical assessment periodically in the follow-up setting, in any event upon admission and every 2 weeks during the first 6 weeks, from then on in any event at important moments regarding the prognosis (3, 6 and 12 months) and with any change in the condition and *prior to* important decisions concerning the treatment, such as the withdrawal of treatment.

It is concluded that, as a 'golden standard' is not available, observational faculties still make up the essence of making the diagnosis 'vegetative state'.

Chapter 6 describes the study into the prevalence in Dutch nursing homes with respect to patients in a vegetative state following acute brain damage and the characteristics of these patients. The study consisted of three steps: interviewing nursing home physicians per telephone following a written notification of the study with an enclosed article on the

diagnostics (chapter 5), an analysis of the lists of questions as completed by the responsible physician and a diagnostic study (in accordance with chapter 5) if there were doubts regarding whether or not the criteria were met. The family was requested to provide written *informed consent* in each case.

The physicians were asked to indicate the number of patients that, in September 2003, met the criteria pertaining to the vegetative state as described in the article on diagnostics. Inquiries were also made regarding the number of patients in a vegetative state that received treatment during the period January 2000 up until September 2003. The end of the treatment of these patients was also recorded, in order to be able to analyse later on whether or not the prevalence could have been influenced by a frequent discontinuation of treatments in the period prior to September 2003.

All of the nursing home physicians that were approached lent their co-operation to the study and they initially identified 43 patients during the interview per telephone who were possibly in a vegetative state that met the criteria. Following an analysis of the lists of questions and an *assessment* of 12 doubtful cases, 32 patients were ultimately found to meet the criteria of a vegetative state lasting longer than one month. Eight of the nine patients that did not comply were in a so-called '*interstitial state*' and one was in a *Minimally Conscious State* with the possibility of carrying out simple assignments. One of the patients with a diagnosis open to doubt was not included, because the family did not give its consent for the data and the *assessment*.

And so the prevalence in the nursing homes was determined to be 5.1 per 10,000 nursing homes beds, corresponding to 2 patients per million of the entire population of the Netherlands, not taking into account any patients in hospitals or in a domestic situation.

Of the 32 patients in a vegetative state, only 30 questionnaires could be analysed, as the families of two patients did not consent to providing additional information. It is evident from the analyses that the average age of the group of patients included in the study is 52.6 years, varying from 9 to 90 years and consisting mainly of women (73.3%). The majority of the patients had been transferred from a hospital and the vegetative state had been caused by a cerebrovascular accident in almost half of the cases. The patients remained in a vegetative state for an average of 6 years, varying from 2 months to 20.3 years. It could not be expected of most of the patients, 26 of the 30, that they would regain consciousness, this based on the cause in relation to the time past. And so the prevalence regarding patients that are in a vegetative state for longer than one year can be calculated at 1.6 per million inhabitants in relation to the Dutch population.

The long-term survival of those in a vegetative state is substantial: 8 patients survived between 5 to 10 years since the incident and 5 patients survived for longer than 10 years (16.7%). A trauma had caused the vegetative state in approx. one-fourth of the patients (8) and three-fourths of these (6) were under the age of 40

When viewed in comparison to the scarce information from literature, the prevalence as found in this study might be considered low. It is concluded that this cannot be explained by the systematic withdrawal of treatment, including tube feeding, in the years before, seeing that this was only reported in 9 of the 43 patients that came to die in the period January 2000 up until September 2003

Now that the prevalence of a nursing home population has been accurately determined for the first time, it is recommended that this study be repeated in order to be able to *monitor* the developments in the prevalence and the factors that are of influence to the prevalence. It is emphasised that strict criteria should be observed in this respect

Chapter 7 describes, in the form of a case study, how a medical intervention at an early stage in the hospital under the direction of a nursing home physician can prevent a hopeless, vegetative state in a nursing home. The case concerns a 52-year-old man who, as a result of prolonged anoxia due to cardiac arrest and a late resuscitation, has been unconscious for 10 weeks at the time that the nursing home physician is called in as a consultant at the hospital. A description is provided of how the diagnostic concept (chapter 5) was used in this case and of the discussion with the family concerning the starting points of the policy (chapter 3). The nursing home physician took over the role of responsible physician from the medical specialist following the transfer to the transfer unit of the hospital. As of that moment, the nursing home physician took charge of a systematic, multidisciplinary treatment plan, so that a clear line of treatment could be set up with clear communications with caregivers and the family. Decisions regarding the treatment as a whole were made based on the central direction of the physician and the contact that had been established with the family. Decisions became unavoidable when the patient developed a sepsis a few days later. That same day, the nursing home physician decided to withdraw the treatment and he personally guided the family intensively by being present until the patient died

It is concluded that the 'waiting phase' in the course of the vegetative state as referred to by the Health Council – namely the phase between the acute phase and the irreversible phase – is pre-eminently suitable for laying the foundation for far-reaching decisions regarding the withholding or withdrawal of medical treatment. The clinical lesson shows that it is precisely

in this phase that the expertise of the nursing home physician can make a difference. In addition, the centrally co-ordinated approach to directing the multidisciplinary care process, combined with the use of the knowledge and experience pertaining to the long-term prospective, are important elements in being able to do that which is advisable and preventing that which is hopeless. This is in keeping with the trend towards further co-operation and the transmuralisation of care.

The last chapter of this thesis, *chapter 8*, concerns a general discussion on the most significant findings. It is concluded that a small number of nursing home patients is in a vegetative state and that there is no standard solution for the dilemmas. It appears from the study that a proactive approach on the part of physicians from the very start is a prerequisite for adequate decision-making in all of the phases of treating a vegetative state. Drawing up multidisciplinary treatment plans at an early stage and clear communications with everyone concerned regarding the objectives constitutes the basis of this approach. The 'waiting phase' following the acute phase appears to be a favourable time to lay the foundation in that respect, in which the transmural possibilities for co-operation between hospitals (physicians) and nursing homes (physicians) can be utilised.

The thesis is concluded with recommendations for in practice, education, research and policy.

Samenvatting

Samenvatting

In dit proefschrift wordt de problematiek van patienten in een vegetatieve toestand beschreven vanuit de invalshoeken diagnostiek, prevalentie en het langetermijnbeloop

De volgende onderzoeksvragen stonden centraal

- 1 Hoe, door wie en op welk moment kan de *diagnose* vegetatieve toestand zo nauwkeurig mogelijk worden gesteld?
- 2 Wat is de *prevalentie* in de Nederlandse verpleeghuizen van patienten in een vegetatieve toestand na acuut hersenletsel en wat zijn de kenmerken van deze patienten?
- 3 Wat is het *beloop en de zorg op de lange termijn* bij patienten die na een acute hersenaandoening in een vegetatieve toestand in een verpleeghuis zijn opgenomen en bij wie geen herstel meer wordt verwacht?

In *hoofdstuk 1* worden deze vraagstellingen in een context geplaatst, waarbij de aanleiding voor het onderzoek wordt toegelicht vanuit historisch, persoonlijk en vakinhoudelijk perspectief. Tevens staat in dit hoofdstuk de opbouw van het proefschrift vermeld.

In *hoofdstuk 2* wordt een praktijksituatie beschreven in de vorm van een klinische les. Dit betreft een 43-jarige vrouw in een vegetatieve toestand, waarbij complicaties met kunstmatige voeding via een neussonde uiteindelijk de directe aanleiding vormden om de totale medische behandeling van de vegetatieve toestand te evalueren. Voor het eerst werd daarbij ook het al dan niet continueren van de sondevoeding betrokken, ook al was daarover nog geen jurisprudentie beschikbaar. Na zorgvuldige toetsing van de besluitvorming werd uiteindelijk besloten om geen PEG-sonde te laten plaatsen, al was de procedure daarvoor gemakkelijker geworden vanwege recente vernieuwingen in de chirurgische techniek. De patiente overleed rustig na het staken van de behandeling.

De conclusie van de klinische les was dat via zorgvuldige besluitvorming een permanente, uitzichtloze vegetatieve toestand voorkomen kan worden. Daarvoor is alertheid voor beslismomenten nodig en de visie dat de behandeling een proces is dat om een regelmatige, totale evaluatie vraagt. Intensieve begeleiding van de familie naar die beslismomenten is daarbij een belangrijke voorwaarde. De casuspresentatie had als boodschap dat het staken van kunstmatige toediening van voeding en vocht als zinloos medisch handelen gezien kan

worden, wanneer dat uiteindelijk niet meer bijdraagt aan het welzijn van de patient Een andere boodschap was dat er na het staken van de sondevoeding een door iedereen als rustig en waardig ervaren stervensproces intreedt voor de patient, hetgeen in schril contrast staat met enkele publicaties in de lekenpers in die tijd

Het langetermijnbeloop in deze casus werd dus vooral bepaald door de complicaties en de besluiten van de behandelend arts ten aanzien van het medisch handelen daarbij, na zorgvuldige toetsing door anderen De uitkomsten van deze casus waren aanleiding om het besluitvormingsproces en het langetermijnbeloop te onderzoeken bij andere patienten in een vergelijkbare toestand

Dat vond plaats door middel van een kwalitatief, descriptief onderzoek in de vorm van *case studies*, hetgeen beschreven is in *hoofdstuk 3* Dit is een eerste beschrijving van 5 patienten die zich langer dan een jaar in een vegetatieve toestand bevonden in een Nederlands verpleeghuis gedurende de periode 1978-2002 Niemand van de beschreven patienten kwam bij bewustzijn De algemene conclusie uit het beloop bij deze patienten was dat de langetermijnzorg en behandeling intensief en complex is met een aanzienlijke co-morbiditeit Het klinisch beloop hangt af van die co-morbiditeit en de houding van artsen en familie ten aanzien van de behandeling in het algemeen, in het bijzonder het wel of niet behandelen van complicaties en het al dan niet voortzetten van kunstmatige toediening van voeding en vocht De houding van de artsen veranderde van voornamelijk reageren op complicaties, naar een meer proactieve rol waarbij een evaluatie van de totale behandeling inclusief sondevoeding het uitgangspunt is geworden Deze benadering past in de ontwikkeling van de verpleeghuisgeneeskunde als medisch specialisme, waarin in toenemende mate een probleemgeoriënteerde, multidisciplinaire werkwijze onder regie van de arts plaatsvindt in plaats van de voormalige reactieve benadering

De chronologische volgorde van de verschillende casus gaf mogelijkheden om leerpunten vanuit elke casus toe te passen in een volgende casus Het leerpunt uit de eerste casus (1978-1989) was dat, in plaats van het abstineren op onderdelen van de behandeling, een regelmatige evaluatie van de totale medische behandeling noodzakelijk is Daarbij bleek in deze casus het onthouden van antibiotica bij een urineweginfectie niet te leiden tot een verwacht overlijden binnen afzienbare termijn, maar tot een chronisch infectieuze toestand met complicaties, waaraan de patient pas jaren later overleed

Het leerpunt om de totale behandeling van de vegetatieve toestand te evalueren werd toegepast in de tweede casus, waarbij complicaties de directe aanleiding vormden om deze

evaluatie te houden. Deze casus is uitgewerkt in hoofdstuk 2 en hierboven reeds beschreven. Deze casus riep de vraag op of een eerdere evaluatie van de totale behandeling, los van complicaties, een uitzichtloze vegetatieve toestand zou kunnen voorkomen

Daartoe werd in de derde casus deze proactieve benadering als startpunt gekozen vanaf de opname van een patiënt, waarbij vanaf het begin helder aan de naasten duidelijk gemaakt werd dat de besluitvorming bij de arts zou liggen en niet bij de familie. Na een intensieve begeleiding van de familie bij het 'toegroeien naar' de beslissing van de arts, werd na een jaar en drie maanden de behandeling inclusief sondevoeding gestaakt. Dit was het kortste beloop in deze *case studies*.

Dit scenario bleek vervolgens niet toepasbaar bij twee andere, jonge patiënten, waarbij de ouders een nieuw evenwicht vonden in het omgaan met de situatie. Zij accepteerden het onthouden of staken van de medische behandeling niet. Op hun nadrukkelijk verzoek werd de behandeling gecontinueerd, ook al waren artsen van mening dat continuering van de behandeling zinloos voor de patiënt was. In de ene casus overleed de patiënt ondanks behandeling aan een pneumonie na bijna 8½ jaar in een vegetatieve toestand te hebben verkeerd. In de andere situatie was er vooralsnog geen andere oplossing dan het continueren van de behandeling na een inmiddels langer dan 16 jaar durende vegetatieve toestand.

Uit dit gedeelte van het onderzoek kwamen aanwijzingen naar voren dat tegenwoordig vooral de houding van de familie ten aanzien van het medisch handelen in het algemeen, en het al dan niet continueren van sondevoeding in het bijzonder, bepalende factoren zijn in het beloop. Er was in dit onderzoek geen standaardscenario om het lot van deze patiënten en hun familie te verlichten, ook al waren artsen in de loop der tijd steeds meer overtuigd dat het medisch handelen niet meer bijdroeg aan het welzijn van de patiënt en daarmee zinloos was geworden. Het staken van de totale medische behandeling inclusief sondevoeding bleek met name acceptabel te zijn voor de partners van de twee patiënten boven de 40 jaar, als zijnde passend bij de veronderstelde wens en waarden van hun naaste. Voor de ouders van 2 jonge patiënten die in de stabiele langetermijnfase van de behandeling een nieuw evenwicht hadden gevonden om met de situatie om te gaan, was het staken van de behandeling ondanks een proactieve benadering van de artsen niet acceptabel.

Uit de beschrijvingen van het langetermijnbeloop in hoofdstuk 3 werd duidelijk dat de behandeling en verzorging van patiënten in een permanent vegetatieve toestand intensief en complex is, met betrokkenheid van meerdere disciplines en medisch specialisten. Er was sprake van een aanzienlijke co-morbiditeit met chronische problemen zoals obstipatie, spasticiteit met contracturen, regelmatige infecties van huid, lucht- en urinewegen, mond- en

tandproblemen en osteoporose met kans op fracturen. Uit het beloop blijkt dat infectieuze complicaties niet altijd lethaal waren, ook al werden ze niet behandeld. Daarnaast was er het risico van een chronische infectie met complicaties zoals abscessen en fistels in een terminale fase. Een belangrijk leerpunt uit de *case studies* was dat het onthouden van antibiotica bij een jonge, wel gevoede patient niet altijd een geschikt scenario lijkt om de patient menswaardig te laten overlijden.

Decubitus werd als complicatie slechts incidenteel waargenomen, en dan met name in de terminale fase. Opvallende bevindingen waren een keratitis filamentosa (beschreven in hoofdstuk 4) en een spontaan herstel van hormoondeficienties na een jaar.

De *keratitis filamentosa* wordt als oogheelkundige complicatie in het langetermijnbeloop nader beschreven in hoofdstuk 4. Het betreft een soort ontsteking van het hoornvlies met ingroei van bloedvaten en vorming van filamenten. De diagnose werd door twee oogartsen onafhankelijk van elkaar gesteld bij twee van de vijf patienten in een vegetatieve toestand, beschreven in hoofdstuk 3. Omdat er vanuit de literatuur geen duidelijk verband met een langetermijnbeloop van een vegetatieve toestand kon worden gevonden, is het fenomeen nader beschreven in de vorm van twee *case reports*. De beschrijving laat zien dat het een chronisch probleem werd in de langetermijnzorg van deze twee patienten. Aanvankelijk werd uitgegaan van de hypothese dat de complicatie veroorzaakt wordt door droge ogen vanwege het onvoldoende knippen van de oogleden. Het jarenlang toepassen van kunsttranen, intermitterende infectiebestrijding met antibiotica/ corticosteroiden en het mechanisch verwijderen van de filamenten, leidde echter niet tot een langdurige remissie. Er waren respectievelijk 36 en 24 episodes van een 'rood oog' gezien, meestal op basis van een *keratitis filamentosa*, die tussen de 1 en 5½ maand duurden. Na 15 jaar werd het beleid veranderd vanuit de nieuwe theorie dat de *keratitis filamentosa* zou kunnen ontstaan door te geringe lidslag van het oog bij patienten die de ogen vaker dicht dan gesloten hebben. Bij een patient werd alle oogmedicatie achterwege gelaten en liet men de ogen geregeld openen door familie en verzorgers. Daarmee kon de langste remissie bereikt worden in het al meer dan 16-jaar durende beloop van een vegetatieve toestand. Tot aan de afronding van dit onderzoek in 2004 – een periode van meer dan twee jaar – is de *keratitis filamentosa* niet meer teruggekeerd sinds de laatste exacerbatie.

Geconcludeerd was dat *keratitis filamentosa* een chronisch probleem kan zijn in het langetermijnbeloop van een vegetatieve toestand met remissies en exacerbaties. Aanbevolen wordt om patienten met recidiverende rode ogen door een oogarts te laten zien, om de

diagnose te laten stellen Tevens wordt opgeroepen om meer van deze bevindingen te rapporteren en nader onderzoek te doen naar een effectieve therapie

In *hoofdstuk 5* wordt vanuit actuele inzichten een diagnostisch concept beschreven als basis voor het medisch handelen op de grens van leven en dood Daarin wordt de vraag beantwoord hoe, door wie en op welk moment de diagnose ‘vegetatieve toestand’ zo nauwkeurig mogelijk kan worden gesteld, met gebruik van eenduidige terminologie en criteria Dit onderdeel van het onderzoek kwam tot stand op basis van de resultaten van een literatuuronderzoek en een bespreking van de discussiepunten daaruit in een expertmeeting De term ‘vegetatieve toestand’ wordt als meest passend gezien voor het toestandsbeeld dat ontstaat als patiënten na een comateuze fase de ogen openen zonder terugkeer van bewustzijn Geconcludeerd wordt dat de diagnostische criteria van de internationale werkgroep *Multi Society Task Force on Persistent Vegetative State* bruikbaar zijn voor de Nederlandse praktijk Daarbij is onderscheid met coma, *locked-in*-syndroom en *Minimally Conscious State* van belang Er wordt een diagnostisch onderzoek voorgesteld dat in de praktijk goed uitvoerbaar en reproduceerbaar is en dat als basis de *Glasgow Coma Scale* heeft, gecombineerd met de systematiek van een gestandaardiseerd onderzoeksinstrument (*Western Neuro Sensory Stimulation Profile*) Centraal daarin staat een systematische, multidisciplinaire diagnostische werkwijze onder regie van een arts, waaraan ook andere disciplines een bijdrage leveren, evenals de familie Deze werkwijze wordt belangrijker gevonden dan het aantal artsen dat erbij betrokken wordt, al dient de in de acute fase gestelde diagnose door de neuroloog of neurochirurg herhaald getoetst te worden door de behandelend arts Toetsing van de diagnose door een onafhankelijk deskundige met ervaring wordt aanbevolen bij twijfelgevallen en vóór belangrijke behandelbeslissingen Periodieke herhaling van het klinisch onderzoek wordt van belang geacht, in de vervolgsetting in ieder geval bij opname en om de 2 weken gedurende de eerste 6 weken, daarna in ieder geval op de prognostisch belangrijke momenten (3, 6 en 12 maanden) en bij elke verandering van de toestand en vóór belangrijke behandelbeslissingen, zoals het staken van de behandeling Geconcludeerd wordt dat, zonder de beschikbaarheid van een ‘gouden standaard’, de vaardigheid van goed observeren nog steeds de kern is van het stellen van de diagnose ‘vegetatieve toestand’

Hoofdstuk 6 beschrijft het onderzoek naar de prevalentie van patiënten in een vegetatieve toestand na acuut hersenletsel in de Nederlandse verpleeghuizen en de kenmerken

van deze patiënten. Het onderzoek bestond uit drie stappen: een telefonisch interview van verpleeghuisartsen na schriftelijke aankondiging van het onderzoek met ingesloten artikel over diagnostiek (hoofdstuk 5), een analyse van door de behandelend arts ingevulde vragenlijsten en een diagnostisch onderzoek (conform hoofdstuk 5) indien er twijfel bestond over het voldoen aan de criteria. In alle gevallen werd schriftelijk *informed consent* gevraagd aan de familie.

De artsen werd gevraagd naar het aantal patiënten dat in september 2003 voldeed aan de criteria van een vegetatieve toestand zoals beschreven in het artikel over diagnostiek. Ook werd gevraagd naar het aantal patiënten in een vegetatieve toestand dat behandeld was geweest in de periode januari 2000 tot september 2003. Van deze patiënten werd tevens het eindpunt van de behandeling geregistreerd, om later te kunnen analyseren of een frequent staken van behandelingen in de periode voor september 2003 de prevalentie beïnvloed zou kunnen hebben.

Alle benaderde verpleeghuisartsen werkten mee aan het onderzoek en zij identificeerden in het telefonische interview aanvankelijk 43 patiënten met een mogelijke vegetatieve toestand conform de criteria. Na analyse van de vragenlijsten en *assessment* van 12 twijfelgevallen, werden uiteindelijk 32 patiënten gevonden die voldeden aan de criteria van vegetatieve toestand langer dan een maand. Van de 9 patiënten die hieraan niet voldeden, bevonden zich er 8 in een zogenaamde 'overgangsfase' (*interstitial state*), en 1 in een *Minimally Conscious State* met de mogelijkheid om eenvoudige opdrachten uit te voeren. Een patiënt waarbij twijfel was aan de diagnose werd niet geïnccludeerd, omdat de familie geen toestemming gaf voor de gegevens en het *assessment*.

De prevalentie in de verpleeghuizen werd daarmee bepaald op 5,1 per 10.000 verpleeghuisbedden, voor de totale Nederlandse bevolking op 2 per miljoen inwoners, waarbij eventuele patiënten in ziekenhuizen en thuis niet meegerekend zijn.

Van de 32 patiënten in een vegetatieve toestand konden 30 vragenlijsten geanalyseerd worden, omdat de familie van twee patiënten geen toestemming gaf voor het verstrekken van nadere gegevens. Uit de analyse blijkt dat de onderzoeksgroep een gemiddelde leeftijd had van 52,6 jaar, met een spreiding van 9 tot 90 jaar, en grotendeels uit vrouwen bestond (73,3%). De meeste patiënten waren opgenomen vanuit het ziekenhuis en hadden in bijna de helft van de gevallen een cerebrovasculair accident als oorzaak van de vegetatieve toestand. De patiënten lagen gemiddeld 6 jaar in een vegetatieve toestand variërend van 2 maanden tot 20,3 jaar. Voor de meeste patiënten, 26 van de 30, kon op grond van de oorzaak in relatie tot de tijd geen herstel van het bewustzijn meer worden verwacht. De prevalentie van patiënten

die zich langer dan een jaar in een vegetatieve toestand bevinden is voor de Nederlandse bevolking daarmee berekend op 1,6 per miljoen inwoners.

De langetermijnoverleving in een vegetatieve toestand is substantieel: 8 patiënten hebben tussen de 5 en 10 jaar overleefd sinds het incident en 5 patiënten langer dan 10 jaar (16,7%). Ongeveer een kwart van de patiënten (8) had een trauma als oorzaak en driekwart van hen (6) was onder de 40 jaar.

Vergeleken met de schaarse literatuurgegevens kan de gevonden prevalentie in dit onderzoek als laag worden beschouwd. Geconcludeerd wordt dat dit niet verklaard kan worden door een systematisch staken van de behandeling inclusief sondevoeding in de jaren daarvoor, aangezien dat in de periode januari 2000 tot september 2003 slechts in 9 van de 43 in die periode overleden patiënten gerapporteerd werd.

Nu voor het eerst nauwkeurig de prevalentie is bepaald van een verpleeghuispopulatie, wordt aanbevolen dit onderzoek te herhalen om ontwikkelingen in de prevalentie en in de factoren die er invloed op hebben, te kunnen *monitoren*. Het hanteren van strikte criteria wordt daarbij benadrukt.

Hoofdstuk 7 beschrijft in de vorm van een casus hoe een vroege verpleeghuis-geneeskundige interventie in het ziekenhuis een uitzichtloze vegetatieve toestand in het verpleeghuis kan voorkomen. De casus betreft een 52-jarige man die door langdurige anoxie vanwege een hartstilstand en een late reanimatie 10 weken buiten bewustzijn is op het moment dat de verpleeghuisarts als consulent in het ziekenhuis wordt ingeschakeld. Beschreven wordt hoe het diagnostisch concept (hoofdstuk 5) werd toegepast en uitgangspunten van beleid (hoofdstuk 3) werden besproken met de familie. Na overplaatsing naar de transferafdeling in een ziekenhuis, nam de verpleeghuisarts de rol als hoofdbehandelaar over van de medisch specialist. Vanaf dat moment voerde deze de inhoudelijke regie over een systematisch, multidisciplinair behandelplan, zodat een duidelijke behandellijn werd opgezet met heldere communicatie met hulpverleners en familie. Vanuit de centrale regie en het opgebouwde contact met de familie, werden besluiten genomen over de totale behandeling. Die waren onvermijdelijk toen de patiënt enkele dagen later een sepsis ontwikkelde. Dezelfde dag besloot de verpleeghuisarts de behandeling te staken en begeleidde zelf de familie intensief door aanwezig te blijven tot aan het overlijden van de patiënt.

Geconcludeerd wordt dat de door de Gezondheidsraad genoemde 'afwachterende fase' – tussen de acute fase en de irreversibele fase – in het beloop van de vegetatieve toestand bij uitstek geschikt is om de basis te leggen voor ingrijpende beslissingen om medische behandelingen te

onthouden of te staken. De beschrijving laat zien dat de expertise van de verpleeghuisarts juist in die fase een bijdrage kan leveren. Daarbij zijn de overstijgende regievoering van het multidisciplinaire zorgproces, gekoppeld aan de inbreng van kennis en ervaring met betrekking tot het langetermijnperspectief, belangrijke elementen om het zinvolle te kunnen doen en het uitzichtloze te voorkomen. Dit past in de trend van toenemende samenwerking en transmuralisering van de zorg.

In het laatste hoofdstuk van dit proefschrift, *hoofdstuk 8*, wordt een algemene beschouwing gegeven over de belangrijkste bevindingen. Er wordt geconcludeerd dat er zich een klein aantal verpleeghuispatienten in een vegetatieve toestand bevindt, en dat er voor de dilemma's geen standaardoplossing is. Uit het onderzoek komen aanwijzingen naar voren dat een proactieve benadering van artsen vanaf het begin een voorwaarde is voor goede besluitvorming in alle fasen van de behandeling van een vegetatieve toestand. Het vroegtijdig maken van multidisciplinaire behandelplannen met heldere communicatie over de doelen met alle betrokkenen is daarvan de basis. Daarbij lijkt de 'afwachterende fase' na de acute fase veelbelovend om die basis te leggen, waarbij de transmurale samenwerkingsmogelijkheden tussen ziekenhuis(arts) en verpleeghuis(arts) benut kunnen worden.

Het proefschrift wordt afgesloten met aanbevelingen voor de praktijk, onderwijs, onderzoek en beleid.

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was bijzonder te noemen, juist op het moment van je kritische ingezonden brief naar aanleiding van mijn eerste artikel, beschreven in hoofdstuk 2. Wie had toen gedacht dat je 14 jaar later medeauteur zou zijn van de *case studies* waarin deze casus ook werd opgenomen? In vriendschap hoop ik nog lang gebruik te maken van je wijze reflecties op het vak, waarin de menselijke maat altijd centraal staat.

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Raymond Koopmans begon in 2000 als copromotor aan dit onderzoek en met zijn benoeming als hoogleraar Verpleeghuisgeneeskunde per 1 maart 2005 werd hij de derde promotor. Raymond, je bent vanaf 1995 mijn maatje binnen de afdeling Verpleeghuisgeneeskunde, aanvankelijk binnen de Vervolgopleiding tot Verpleeghuisarts (VOVA), maar de laatste vijf jaar ook in onderzoek. Bedankt voor alles wat ik van je geleerd heb, zeker met betrekking tot de methodologie en de wetenschappelijke scherpte. Met bewondering zag ik hoe je tijdens mijn onderzoeksperiode een nieuwe infrastructuur voor academisering hebt opgebouwd. Het voelt goed om daaraan samen verder te bouwen. Behalve vanuit mijn rol als hoofd van de VOVA, kan ik dat nu ook als wetenschapper doen. Ik ben er trots op dat we in 2005 verschillende mijlpalen in ons vak met elkaar zullen vieren. Op die momenten zal ik onze eerste hoogleraar Verpleeghuisgeneeskunde, Joop Michels, missen. Hij vroeg bij elke ontmoeting hoe het met de promotie was, maar kan het resultaat helaas niet meer meemaken.

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Mijn collegae verpleeghuisartsen in het land ben ik zeer erkentelijk voor het feit dat iedereen meewerkte aan het prevalentieonderzoek. Die transparantie is bijzonder in deze gevoelige materie en mijn trots op onze beroepsgroep zal ik dan ook overal in binnen- en buitenland overbrengen.

Ik dank ook de familieleden van de betrokken patiënten in dit onderzoeksgedeelte voor hun medewerking aan het naar buiten brengen van de gegevens.

De medewerkers van de VOVA dank ik voor de wijze waarop zij het mogelijk maakten om mijn twee banen strikt gescheiden te houden. Ik ben er na vijf jaar nog steeds trots op leiding te mogen geven aan een team vol enthousiasme, creativiteit en humor met daarbij een goede balans tussen daadkracht en reflectie. Secretariaresse Mathilde van Dalen schermde daarbij mijn onderzoeksdagen goed af van de werkzaamheden van de VOVA, zodat ook ik een goede balans kon behouden in beide rollen. Statisticus Hans Bor dank ik voor zijn bijdrage aan het automatiseren van de gegevens en de statistische bewerkingen.

In de afwerking van het manuscript dank ik Anne-Miek Goossens voor de tekstuele adviezen bij de Nederlandstalige stukken en Hans Hoekman en Nancy Christiaans voor hun hulp bij de

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Dankzij bemoeienis van president George Bush met een patiënte in een vegetatieve toestand in Amerika, Terri Schiavo, kreeg mijn onderzoek veel publiciteit op het moment dat het gereed was. Toch dank ik hem daar niet voor. Wel dank ik Joke Groeneveld, Anselien School en Walther Verhoeven van Staf Concerncommunicatie van het UMC St Radboud voor de voortreffelijke wijze waarop ze de publiciteitsgolf opvingen en met me samenwerkten.

Voor het indalen vanuit het hoofd naar het hart ben ik de mensen van Argentijnse tangoschool 'El Corte' (Eric, *et al*) dankbaar. Vooral het wekelijks dansen met mijn tangopartners Anja en Nicky (*'there is always a tango'*) was belangrijk voor het handhaven van de juiste balans.

Ik ben vereerd met mijn paranimfen Marlie Spijkers en Maaïke Veldhuizen. Jullie zijn zielsverwanten in het vak en fijn dat jullie ook op deze speciale dag achter mij staan. Ik hoop dat wij elkaar nog lang kunnen inspireren.

Aan mijn ouders draag ik dit proefschrift op. Jullie legden eens de solide basis voor het leren in dit leven, waarbij de juiste mix van hart, verstand, geloof en vertrouwen me nog vaak van pas zal komen.

Voor alles wat met het hart en de ziel te maken heeft, ben ik Anja alle dank verschuldigd. Dankzij jou was het thuis altijd een oase van rust en bezieling en viel alle hectiek van twee banen bij het oprijden van de dijk onmiddellijk van me af. Bij de start van dit onderzoek schonk je me de workshop *'Creating the work you love'*. Dit onderzoek heeft voor mij op alle momenten beantwoord aan die titel, maar dat was niet mogelijk geweest zonder de ruimte die jij ervoor gaf.

En tot slot, lieve Elian, hield jij me vooral in balans. Sinds jij als wonder in mijn leven kwam, ontdek ik in mijzelf telkens nieuwe dimensies als ik je blauwe ogen zie.

CURRICULUM VITAE

Jan Lavrijsen is geboren op 11 mei 1960 in het Brabantse Middelbeers. In 1977 behaalde hij het diploma Gymnasium- β , waarna hij uitlootte voor de studie Geneeskunde. In het parkeerjaar 1978 volgde hij de HBO-opleiding Verpleegkunde (HBO-V) te Eindhoven, waar hij tijdens een stage voor het eerst in aanraking kwam met het werken in een verpleeghuis. Dat boeide hem zo dat hij jarenlang vakantiewerk deed in het Kempisch Verpleegtehuis te Bladel en in Het Dorp te Arnhem.

Van 1979 tot 1985 studeerde hij geneeskunde in Maastricht en raakte gefascineerd door het probleemgeoriënteerde onderwijs.

Na afstuderen werd de combinatie geneeskunde en onderwijs een rode draad in zijn carrière. In 1985 was hij docent Geneeskunde aan de HBO-V te Eindhoven, juist in de overgangsfase naar probleemgeoriënteerd onderwijs. Na het docentschap bleef hij enkele jaren verbonden aan deze opleiding via de Begeleidings Advies Commissie.

In 1986 vervulde hij zijn vervangende dienstplicht als arts en docent geneeskunde in de verpleeghuizen St-Jozefsheil en Jan de Wit-kliniek te Bakel, deel uitmakend van de huidige Stichting De Zorgboog. In 1988 kwam hij, na een reis van een half jaar door Azië, in vaste dienst. Vanaf 1992 werd hij in Bakel verpleeghuisartsopleider, maar stopte daarmee toen hem in 1995 gevraagd werd om de Vervolgopleiding tot Verpleeghuisarts (VOVA) van het huidige UMC St Radboud in Nijmegen mee op te starten. In maart 1995 werd hij daar de eerste verpleeghuisartsbegeleider. Van 1996 tot 2000 werkte hij in het verpleeghuis De Lingehof te Bommel, deel uitmakend van de Stichting Oranje Nassau Oord te Renkum. In de eerste jaren tot de bouw van dat verpleeghuis gereed was, werkte hij in de Overbetuwe als verpleeghuisarts zonder verpleeghuis. Daarnaast vervulde hij in de periode 1998 tot 2000 de functie van onderwijscoördinator aan de VOVA.

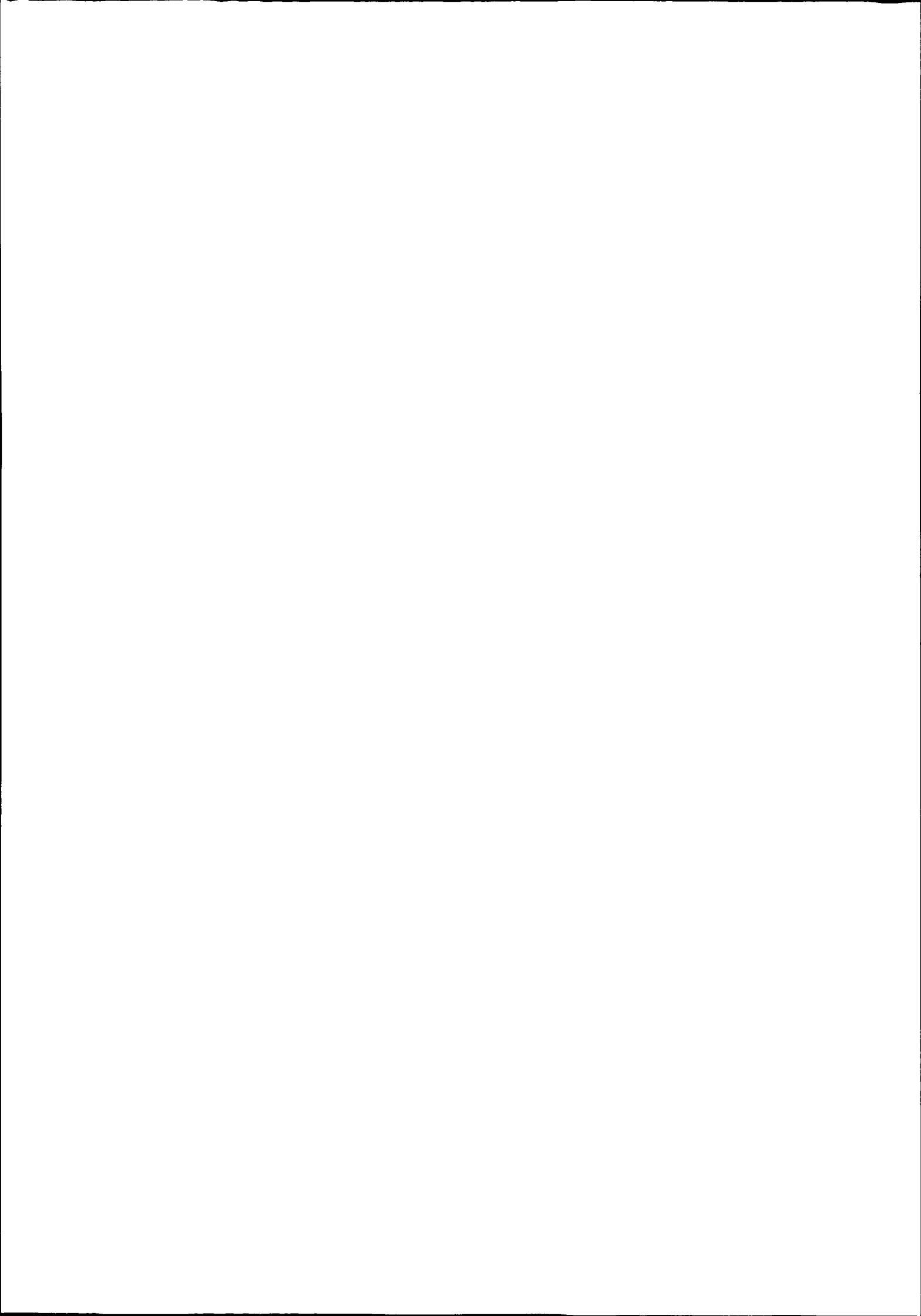
In 2000 werd hij hoofd van de VOVA en startte tevens voor twee dagen per week dit promotieonderzoek in dienst van De Zorgboog te Bakel.

Als nevenactiviteit was hij onder andere jarenlang redactielid van het Tijdschrift voor Verpleeghuisgeneeskunde en lid van de begeleidingscommissie van het laatste landelijke evaluatieonderzoek naar de medische besluitvorming aan het einde van het leven.

STELLINGEN

behorend bij het proefschrift 'Patients in a vegetative state: diagnosis, prevalence and long-term care in Dutch nursing homes' van Jan Lavrijsen

1. In de behandeling van patiënten in een vegetatieve toestand is er altijd een weg terug, al blijkt het in praktijk moeilijker om die weg in te slaan naarmate je langer onderweg bent.
2. Wat de behandeling van patiënten in een vegetatieve toestand betreft, zijn er meer wegen die naar Rome leiden. Dit is echter niet op alle plaatsen in Rome voelbaar.
3. Het zorgvuldig afzien van zinloos medisch handelen is ook 'intensive care', maar voor buitenstaanders vaak minder spectaculair.
4. Onze onmacht met de stervende te leven en het wachten op de dood met hem of haar uit te houden, wordt niet adequaat opgelost door het veroorzaken van een door ons gewilde kunstmatige dood. (prof. Paul Sporken †)
5. Soms is het beter niets te weten dan een beetje.
6. *'It takes two to tango'* geldt in verpleeghuizen met name voor de samenwerking tussen arts en verpleging: een mooie dans als beiden krachtig ervoor staan, maar kwetsbaar als er een uit balans is.
7. De kenmerken van patiënten in een vegetatieve toestand bevestigen dat de term 'algemeen geriater' niet de lading dekt van het werk van verpleeghuisartsen.
8. Verpleeghuisartsen voorkomen met hun handelen veel ongewenste en zinloze behandelingen in ziekenhuizen. Zij zouden dat door onderzoek meer naar buiten moeten brengen, zodat ook beleidsmakers beseffen dat dit een aanzienlijke besparing van ellende en kosten betekent.
9. Promovendi kunnen elkaar niet altijd een hand geven vanwege schouderklachten door het langdurig werken achter laptops en het dragen van zware tassen. Schouderklopjes werken dan averechts.
10. Periodiek stilstaan door reflectie op gebeurtenissen en handelen is belangrijk om vooruit te komen. Dit kan beter op het werk gebeuren dan thuis.
11. In een land waar meerdere rechters en politici op de bedrand gaan zitten van een stervende patiënt in een vegetatieve toestand, regeert het wantrouwen.
12. Als de hoog gewaardeerde tijd en aandacht voor mensen wat meer op lijsten van prestatie-indicatoren zou verschijnen, halen verpleeghuisartsen de top.





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