

## The Experiences and Opinions of Dutch Stroke Patients Regarding Early Hospital Discharge and Subsequent Rehabilitation Assessment and Planning in a Nursing Home

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### Abstract

**Introduction:** A new stroke care model has been developed in Maastricht, The Netherlands, in which patients only receive short-term acute care in the hospital. As soon as they are stabilized, patients are transferred to a special assessment and rehabilitation unit in a nursing home where the optimal rehabilitation track will be determined by means of a structured multidisciplinary assessment. It is not yet known how stroke patients experience this new care model and what their opinions are on it.

**Objective:** To explore stroke patients' experiences with and their opinions on this newly developed stroke care model.

**Methods:** Qualitative study among stroke patients admitted to the Maastricht University Medical Centre between September 2010 and January 2011, who underwent a multidisciplinary assessment in a nursing home as part of a newly developed stroke care model. Each link (hospital stay, transfer to and stay in the nursing home and return home) of this new care model was assessed by means of semi-structured interviews.

**Results:** Fourteen interviews were performed. Stroke patients stated that in general everything was well cared for and organized. They did not experience distorting problems with the care delivery. However, more attention has to be paid to the communication with the patients and their partners concerning the rehabilitation track.

**Conclusion:** The newly developed stroke care model is well experienced by patients. If this way of organizing stroke care appears to be cost effective, the next step will be implementation in more nursing homes.

**Keywords:** Stroke service; Patients' experiences and opinions; Multidisciplinary assessment; Nursing home

### Introduction

Strokes have a profound effect on a person's life and also present a large economic burden to society [1]. Changes in delivery of healthcare, driven by the need to optimize the delivery of care and reduce costs, have resulted in shorter hospital stay and a decrease in the number of acute care beds in hospitals [2]. It is estimated that in the Netherlands the prevalence of stroke will rise until 2025 [3]. Accordingly, managing the growing number of patients suffering from strokes demands creative solutions without negative impact on stroke outcomes.

Early discharge from hospital followed by assessment of stroke-induced disabilities and rehabilitation planning in a nursing home setting might be a solution for the Netherlands, where 45% of stroke rehabilitation for especially older stroke patients takes place in nursing homes [4]. In contrast, only 13% of the stroke patients in the

Netherlands rehabilitate in specialist rehabilitation clinics. These are mostly younger patients who still participate in employment [4]. The stroke service Maastricht-Heuvelland introduced an innovative care model aimed at reducing hospital stays for stroke patients to five days, followed by assessment in a nursing home. The transition of the multidisciplinary assessment and treatment from the hospital to the nursing home should reduce delay in the rehabilitation track by withdrawing double work and unnecessary waiting [5].

In this new stroke care model, every stroke patient is admitted primarily to the Maastricht University Medical Centre's (MUMC) stroke unit. In the emergency ward, acute diagnostic tests are performed. In case of a confirmed stroke, the patient will be admitted to the stroke unit of the MUMC, where further diagnosis and treatment, including thrombolysis if indicated, are performed. Subsequently, the new stroke care model consists of a strict discharge regime from the neurology ward of the MUMC. All necessary tests and treatments in the hospital are planned within the first five days after admission. Thereafter, in principle, all stroke patients, regardless of age, are discharged to the stroke ward of a nursing home, where a

comprehensive assessment takes place. Only patients who can be discharged home within five days after admission and those who are medically unstable will not be transferred to the nursing home. A skilled elderly care physician examines each patient immediately after arrival in the nursing home and initiates the assessment program. In this program, a multidisciplinary team consisting of a physiotherapist, occupational therapist, psychologist, speech therapist and trained nurses, examines the patient, by performing a structured assessment protocol. Following this assessment, the team will meet within five days of the patient's admission to the nursing home to make recommendations for a rehabilitation program specifically tailored to the patient. Rehabilitation can take place at home with outpatient care or by means of inpatient rehabilitation in a nursing home or a specialized rehabilitation centre. The development and implementation of this care model are described elsewhere [6].

During an earlier evaluation of this newly developed stroke care model, Van Raak et al. [7], in a single case study, found some issues threatening the model, namely the transport of stroke patients from the MUMC to the nursing home, a lack of communication between the different disciplines in the MUMC and nursing home and a lack of communication between caregivers and patients. They studied documents, interviewed managers and observed the care pathway, but they did not pay attention to patients' experience and opinions.

As part of a cost-effectiveness study of which the full protocol has been published elsewhere [8], this paper describes the outcomes of a qualitative study, identifying stroke patients' views on early discharge to and assessment in a nursing home, as part of the new stroke care model. Although effects and costs are important aspects for healthcare policymakers to base their decisions upon, we purposively aimed at describing any adverse effects as seen through the eyes of the patient.

The question we wanted to answer in this qualitative study was: What are the experiences and opinions of stroke patients with this newly developed care model?

## Methods

### Study design

A qualitative study design was used in which patients' experiences and opinions were assessed by means of semi-structured face-to-face interviews. We chose this method because it gave us the opportunity to discuss thoroughly the experiences of patients with the new stroke care model [8,9].

### Recruitment and sampling

This qualitative study was part of a larger study, comparing cost effectiveness of the new stroke care model to care as usual [10]. All stroke-patients admitted to the neurological ward in the MUMC were given oral and written information about the main study during their hospital stay. The diagnosis of stroke was made by a neurologist based on patient history, physical examination and neuro-imaging. Patients needed to be over 18 years of age and speaking Dutch to participate in the study. Patients with a life expectancy of less than a few days, with a previous diagnosis of dementia, hospital discharge to home within a few days or the occurrence of complications, which required prolonged hospital care, were excluded from participation.

Between 20-10-2010 and 10-01-2011 patients were also informed about this qualitative study and could give written informed consent

separately on this part of the study. We aimed to sample patients purposively regarding their route through the new stroke care model. For patients to be eligible to participate in the study, they needed to be exposed to the intervention as intended. About 4 weeks after admission to the MUMC, patients were visited and interviewed in their current living-situation. We chose this period as being long enough to ensure the assessment to have been finished and short enough to ensure that patients would still remember their experiences and emotions during hospital stay. We expected that data saturation would be reached after about 15 interviews. For this reason the number of patients to be included was 15-20 participants.

### Data collection

To ensure the open character of the interviews, they were performed by an independent interviewer, who was not directly related to the project group. She was a final year medical student at the Maastricht University at the time of the study and trained in taking open interviews. A topic list was developed for this study, based on the framework of the complex care innovation [10]. The main topics were the experiences during hospital stay, during transfer from hospital to the nursing home, and during the stay in the nursing home and, if applicable, after returning home again. Questions involved opinions on length of stay, experiences on the way patients were treated by healthcare providers, the organization of care and the information supply. All interviews were audio taped and transcribed verbatim.

### Analysis

The interviews were analysed by directed content analysis [11]. After identifying and coding text passages relevant to the research question, the descriptive codes were compared and contrasted by sequential and retrospective searching within and among the interviews. The codes were then grouped into larger themes, explored further, structured, refined and reduced in number. Data was collected and analysed concurrently, allowing both expected and emergent themes and ideas to be incorporated and explored in subsequent interviews. Units of text referring to similar codes were grouped and categorized systematically by one central coder, who coded all the interviews. For the six richest interviews, the central coder and a second coder independently executed a full open coding of the transcript. Differences in coding were resolved by consensus discussion. The central coder then analysed the other interviews and the codes were checked by a second coder [12].

## Results

### Study population

We included 14 stroke patients in the study to assess their experiences and opinions with the redesigned stroke service. During the inclusion period it appeared that too few patients were participating in the study. Therefore, besides including acute stroke patients, we also looked back about five weeks, from 13-09-2010 till 20-10-2010 to ask patients retrospectively to participate in the interviews. We did this to be certain that we would manage to include enough patients. During two interviews the patient's partner was present.

Table 1 shows patient and interview characteristics (time, place, length) of the participating patients. The average age was 72.7 years (SD 6.1 years) with a range of 65-86 years, 8 of these patients were

female, 13 had a cerebral infarction, and 1 an intracerebral haemorrhage. The length of hospital stay varied from 4-16 days, with the average length of stay being 8.5 days (SD 3.1 days).

The interviews took place on average 43.6 days (SD 23.1 days) after admission to the MUMC, with a range of 29-107 days. In 91% of the cases the place of residence of the patient, at the time of the interview, was the nursing home, and in 9% their own home. The length of the interviews was on average 24.6 minutes (SD 9.3 minutes) with a range of 14-45 minutes.

Patient characteristics	n=14
- mean age (SD) in years	72.7 (6.1)
- range in years	65-86
- % male/female	43/57
- intracerebral haemorrhage/infarction	1/13
<b>Length of hospital stay</b>	
- average (SD) in days	9.0 (3.2)
- range in days	4-16
<b>Interview characteristics</b>	
Time after admission to MUMC	
- mean (SD) in days	43.6 (23.1)
- range in days	29-107
- place of residence % home/nursing home	9 / 91
<b>Length of interview</b>	
- mean (SD) in minutes	24.6 (9.3)
- range in minutes	14-45

**Table 1:** Patient and interview characteristics of the study population.

### Hospital stay

Four patients hadn't any recollection of their hospital stay, the others described it as strange, being in a foreign environment, hectic, tiresome and patients felt dependent. For the patients it was a difficult period, they just had a stroke and thus couldn't process everything around them with a lot of things happening at the same time.

"You know, there is so much coming at you, you're in a foreign environment. It's all so difficult to comprehend at that moment, you are concerned about your own situation, not with all the things surrounding you, in a way, you just let it come over you".

However, none of the patients mentioned their stay in the hospital as being too busy or too short. Most patients thought their stay was long enough and some of them were even happy to go to the nursing home, due to the change of scenery and the fact that they could start their therapy there. One of the patients felt that the hospital stay was too long. This involved a stay of 16 days, which was the longest in the study population. One of the patients expressed negative experiences about the hospital stay and was rather emotional during the interview, because, during the stay in hospital this patient was tied to the bed. This patient also judged the nurses in the hospital as being strict. Generally, the patients judged the nurses to be adequate professionals,

as they guided the patients where needed. Patients reported about tests being done in the hospital, but only one patient reported to have been exposed to therapy. Overall, patients stated that the information supply was deficient. Most of the times patients mentioned to be sufficiently informed about their medical condition, but stated that the consequences of their condition and the further care pathway were hardly explained. Also, one of the patients' partners mentioned that the information she got herself was inadequate, since she couldn't receive information from her husband.

"What kind of tests was performed in hospital? I wouldn't know, we find the hospital did not inform us very well. We had to ask everything ourselves, and that was very annoying. My husband couldn't tell me whom he had seen. I found it very difficult that I was not informed of how he was doing or what tests were performed".

### Transfer from hospital to nursing home

Most patients reported to have been informed about the transfer to the nursing home, but further explanation about why? was deficient. The only additional explanation or reason given for this transfer was in some cases that they would get therapy then and that the rehabilitation would start in the nursing home. It was only seldom mentioned that early and tailored determining of the best rehabilitation track was an important goal of the transfer. One of the patients mentioned that a therapist in the hospital had remarked, one day before discharge that they couldn't do more at the nursing home, than already had been done in hospital and in her opinion the patient could go home. However, this needed to be discussed with the neurologist, who only came one hour before discharge from the hospital. This patient was hoping to go home and was uncertain for quite some time.

Most patients were transferred to the nursing home with an ambulance, others went by transport provided by family. All patients were satisfied with their means of transport. In most instances one of the family members or another close acquaintance of the patient accompanied the patient, which was experienced as pleasant and supporting.

### Stay at the nursing home assessment unit

Some of the patients reflected on the large differences in severity of impairments between the patients staying at the nursing home assessment unit. Patients with cognitive impairment stayed at the same ward as patients with hardly any cognitive problems. Some of the patients thought this was not helpful for their recovery and they would like these groups to be separated. Generally however, everything was experienced as well cared for and arranged in the nursing home rehab unit. One of the patients mentioned that medication in the morning was sometimes left behind in the bedroom or bathroom. Three patients complained of a lack of privacy.

"I have been in the nursing home for four days. There is no privacy there. It was embarrassing, I stayed in a room with three ladies; well the curtains were closed, but still you hear everything. In my opinion that's not right".

Patients indicated they couldn't remember everything that happened in the beginning when they arrived at the nursing home because of the many new impressions they had to process. As far as people remembered, they judged the information given to them at admission as good. There was a guided tour through the nursing home, an intake took place, and the program for the assessment as well as the

subsequent rehabilitation programme was explained. However, the most important issue for the patients was getting home as soon as possible. The patients were motivated to recover, they were eager to learn how to walk again, and as long as they saw progress they accepted their stay at the nursing home.

Most of the times patients could not really distinguish between the assessment in the beginning and the actual rehabilitation track that followed. Some of the patients mentioned there had been a screening in the hospital, just like the one they got in the nursing home, so this was kind of a repetition, which they thought was needless. In general patients experienced the assessment not as annoying. The nursing home professionals involved in the assessment and therapies were viewed as nice and kind. They gave good guidance and support, explained what they wanted to do, and everything happened in a calm way. None of the patients experienced the assessment as being too busy, some of them saw it as a distraction from their daily routine. Since some patients did not process everything in the beginning that well, they could not remember the overall advice given at the end of the assessment. The fact that their progression was discussed after a period was experienced as favourable, since patients could process this information better at a later point during their stay in the nursing home.

The nurses on the ward were described as good, sometimes even great, kind, helpful and humane. Some patients were disturbed by the noise nurses made, especially during the night or in the early morning and others would like nurses to interact more with them and sometimes chat to them. Some patients expressed their concerns for the nurses' job quality.

"They are all nice girls, really. But they have to run all day long. They are very busy and yet they stay polite. They work under pressure and it's difficult to stay polite, under pressure. I think they are trained for it".

Patients felt that, besides the therapies, there were few other rehab stimulating activities resulting in patients often just sitting in their chairs when they had no formal treatment sessions. This was regarded as annoying by some patients. Most patients liked and could understand the treatment approach that was followed during the rehabilitation, which involved that they had to do things themselves as much as possible, and that they only got help when needed.

## Return home

Some of the interviewees already had returned to their own home or would do so on short term. These patients were content about the time in which everything was arranged and they mentioned that at a certain point they were ready to go home and were looking forward to it. Patients thought it was favourable to first have a home visit or a weekend leave before they returned home permanently, because this made them more confident.

They experienced it as nice that therapists made one or more home visits with them before discharge. These visits were part of the structural evaluation before returning home. Patients felt satisfied about the guidance from the nursing home related to the transition to their original home situation; it happened in a nice way, not threatening, and a lot of tips were given, also for their partners. In the new stroke care model patients are also visited at home by a home care coordinator a few weeks after their nursing home discharge. This is a specialized stroke nurse who assesses the actual home situation after discharge and organizes extra help if needed. None of the interviewees had been visited by the homecare coordinator yet, but some had an

appointment and they thought it was a good initiative to check the situation a few weeks after returning home.

## Discussion and Conclusion

The interviewed stroke patients involved in this new stroke care pathway stated that in general everything was well cared for and organised during their rehabilitation track. They did not experience distorting problems with the care delivery. Some patients complained of a lack of privacy in the nursing home, a lack of activities in the nursing home, the repeating of screenings or of lack of communication on the rehabilitation track in the hospital phase.

## Comparison with existing literature

Since our study is among the first to explore the experiences and opinions of stroke patients on redesigned care processes under study, few is known about this subject.

Causes of privacy disturbance, such as multiple-occupancy rooms, and limited efforts by caregivers to reduce noise, as mentioned by our patients during the stay in the nursing home setting, were also found by others [13]. A single-occupancy room favours privacy and allows families to participate in care. In the Netherlands, over the last years general improvements are being made in patients privacy, aiming at all patients having their own room in the nursing home rehabilitation setting.

The lack of activities between rehab therapies, as stated by our patients, is consistent with the quantitative findings of Spruit et al. [14]. They found that stroke patients in a nursing home setting spent 43.5% of the day on non-therapeutic activities (mostly sitting, laying). The role of nurses is seen as very important in assisting patients to engage in therapeutic and other activities [15,16]. But as our patients also mention, the workload of nurses is seen as heavy and without more resources this will become even heavier, as stroke incidence will rise over the coming years, leading to survival of more and more patients with cardiovascular diseases, who need complex (rehab) care services, that have to be provided in a time in which care organizations continuously face budget cut [3].

The transition of the multidisciplinary assessment and treatment from the hospital to the nursing home should reduce delay by withdrawing double work and unnecessary waiting [5,14]. However, in our interviews patients reported there is still double work being done, namely a sort of assessment done in the hospital, which was repeated more extensively in the nursing home. This suggests even more time can be saved by better attuning of the assessments. The question is whether this time can be saved in the hospital or in the nursing home, or maybe even in both.

In 2006 it turned out that the transport of patients from the hospital to the nursing home was a weak link in the stroke care chain [17]. The main reasons for this problem was that ambulance services were not assigned to this task and patients often had to wait or arrange their own transport. New appointments were made to resolve this problem and from our interviews we can conclude that most of the patients are transferred using an ambulance, but also family members and other close contacts of the patient are still asked to transport the patient. However none of the patients reported having had problems with their means of transport.

With the implementation of the newly developed integrated care pathway for stroke patients, a faster care delivery has been established,

initiated in the nursing home setting where all patients could start their rehabilitation track after 3 days of assessment. Although the patients in our study are generally satisfied with the medical information given to them by nurses and physicians, they complain about a lack of timely information supply concerning their individual care pathway. Good and timely communication with the patient and their partners about the care pathway is necessary. A case manager that follows the patient through the care pathway and provides timely information could be a solution for this problem.

### Strengths and limitations

The most important strength of this study is that, as far as we know, this is the first to evaluate patients' experiences with and their opinions on a newly developed integrated care pathway for stroke patients. We included a diverse sample of stroke patients, e.g. both sexes, different ages and different stroke types (infarction as well as intracerebral haemorrhage).

We did not manage to include 15-20 patients, as was our primary goal. Though only 14 patients could be included, this doesn't mean that their opinions and experiences are less meaningful or significant. Moreover, we think we performed enough interviews to reach data saturation, as we did not distract new findings after 10 interviews. All interviews were audio taped and transcribed verbatim, except for one due to technical problems. During this interview the interviewer took notes and transcribed these directly after the interview.

Most patients were still staying in the nursing home at the time of the interview. This means that the patients are still dependent on the staff at the nursing home and that they may not have been completely open about the aspects concerning their stay at the nursing home. We tried to avoid these influences by using an independent interviewer. Before every interview we also emphasized that all answers given would be treated confidentially, processed anonymously and that the audiotapes would only be used by the interviewer to work out the interviews.

During the interviews it appeared that patients did not pick up everything in the acute phase, and thus remembered little about this period. Because of this, the findings concerning the acute phase may be incomplete. One can doubt whether the patients who were dissatisfied about the information they got in the hospital, really did not get information, or just did not remember it. However, one of the patients' partners also stated that the information supply in the hospital was suboptimal.

### Implications

In general, the patients stated that they were well cared for and that they did not experience any significant problems with the newly developed integrated care pathway. The preliminary outcomes of the cost effectiveness study are in support of the new care model and the qualitative findings in this paper show that patients' experiences are not obstructing its implementation either. However, more attention has to be paid to good and timely communication with patients and their partners. Future studies might provide more insight into the prolonging effects of this new stroke model and in the course of the perspectives and experiences of patients, family caregivers and care providers involved in it.

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The Medical Ethical Committee of Maastricht University has granted ethical approval. The trial is registered as ISRCTN58135104. The authors declare that they have no conflict of interest.

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