

Involving caregivers of stroke survivors in training programs: a feasibility study

Name	Annette Kleijburg
Student no.	3361403
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University	KGW Master Verplegingswetenschap, UMC-Utrecht
Mentor	Dr. T. B. Hafsteinsdóttir
Tutor	Drs. J. de Man - van Ginkel
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Abstract

Involving caregivers of stroke survivors in training programs: a feasibility study

Aims and objectives. To investigate the feasibility and practicality of a nurse led training program for stroke survivors and their caregivers within a stroke rehabilitation ward.

Background. An increased intensity of training activities improves functional outcomes in stroke survivors. This can be achieved by the involvement of caregivers. Involving caregivers in training has positive effects on psychosocial outcomes of patients and caregivers.

Design. A quantitative, descriptive design was used to evaluate the feasibility and practicality of the training program Fast Forward as experienced by nurses, patients and caregivers.

Methods. The training program Fast Forward, where caregivers were involved in exercising with patients under supervision of nurses, was implemented on two stroke units in a rehabilitation centre. The feasibility and practicality for nurses, patients and caregivers was evaluated using a self developed questionnaire including (open) questions about nurses, patients and caregivers' experiences in using the training program.

Results. Eleven nurses, 13 patients and 13 caregivers took part in the study. Nurses were positive regarding the feasibility and practicality of the intervention. Of the 13 couples six (46.2%) exercised together, evaluating the intervention as important, valuable and fitting their needs. The amount of training activities among these patients probably increased.

Conclusion. Nurses, patients and caregivers general were positive about involving caregivers in the training of patients. Nurses, however, showed little adherence to the intervention, causing few patients and caregivers doing shared exercises. Thorough attention should be expended to the implementation of the intervention to make nurses actually perform it.

Relevance to clinical practice. Involving caregivers in training activities of stroke patients may be seen as an important way of improving activity and rehabilitation. Implementation should focus on nurses' motivation, skills and knowledge, as well as on commitment to goal and task setting within the whole rehabilitation team. Further research is needed

Key words: stroke, rehabilitation, caregiver, training program, feasibility

Nederlandse samenvatting

Mantelzorgers van patiënten met beroerte betrekken in trainingsprogramma's: een haalbaarheidsonderzoek.

Doel: Onderzoek naar de haalbaarheid en bruikbaarheid van een door verpleegkundigen geleid trainingsprogramma voor patiënten met beroerte en hun mantelzorgers, op een stroke-afdeling in een revalidatiecentrum.

Achtergrond: Verhoogde trainingsintensiteit leidt tot verbetering van functionele uitkomsten bij patiënten met beroerte. Dit kan worden bereikt door mantelzorgers te betrekken in trainingsactiviteiten. Het betrekken van mantelzorgers heeft een positief effect op psychosociale uitkomsten bij patiënten en mantelzorgers.

Studiedesign: Een kwantitatief, beschrijvend design werd gebruikt voor de evaluatie van de haalbaarheid en bruikbaarheid van de oefengids Snel in Beweging (SIB), zoals ervaren door verpleegkundigen, patiënten en mantelzorgers.

Methoden: Mantelzorgers begeleidden patiënten bij het trainen met de oefengids, onder supervisie van verpleegkundigen. De haalbaarheid en bruikbaarheid van deze verpleegkundige interventie zoals ervaren door verpleegkundigen, patiënten en mantelzorgers werd onderzocht met behulp van zelf ontwikkelde vragenlijsten.

Resultaten: Elf verpleegkundigen, 13 patiënten en 13 mantelzorgers participeerden in de studie. Verpleegkundigen waren positief wat betreft de haalbaarheid en de bruikbaarheid van de interventie. Van de 13 koppels trainden er zes (46,2%) samen. Zij vonden de interventie belangrijk, waardevol en aansluiten bij hun behoeften. Waarschijnlijk nam het aantal trainingsactiviteiten onder de patiënten die samen met hun mantelzorgers oefenden toe.

Conclusie: Verpleegkundigen, patiënten en mantelzorgers waren positief over het betrekken van mantelzorgers bij trainingsactiviteiten voor patiënten met beroerte. Verpleegkundigen pasten de interventie in beperkte mate toe, waardoor weinig koppels samen oefenden. Een zorgvuldige implementatie is noodzakelijk om verpleegkundigen de interventie daadwerkelijk uit te laten voeren.

Klinische relevantie: Het betrekken van mantelzorgers in trainingactiviteiten kan een belangrijke bijdrage leveren in de revalidatie van patiënten met beroerte. Implementatie van de interventie moet gericht zijn op de motivatie, vaardigheden en kennis onder verpleegkundigen, maar ook op inzet voor de doelen en taken binnen het hele revalidatiebehandelteam. Vervolgonderzoek is noodzakelijk.

Zoektermen: beroerte, revalidatie, mantelzorger, trainingsprogramma, haalbaarheid

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Introduction

Stroke is one of the leading causes of adult disability in the Western World (Lloyd-Jones *et al.*, 2009). In 2007 in the Netherlands the prevalence of stroke was 191.000 and the incidence was 35.600 (Hoeymans *et al.*, 2010). The mortality rate following stroke is 25% within the first four weeks. About 50% of the stroke survivors suffer from long term physical, cognitive and psychosocial disabilities (Hafsteinsdóttir & Schuurmans, 2009). Approximately one-third develop post-stroke depression (Robinson, 2003) and may experience associated reductions in quality of life (Teasell *et al.*, 2003).

Stroke also has major consequences for family caregivers. Stroke is a sudden event and caring partners enter their new role abruptly, often without the opportunity to adjust to the change and learn new skills (Draper & Brocklehurst, 2007). Approximately 35-50% of the family caregivers are burdened by the caregiver role (Van Exel *et al.*, 2005) and 51% have symptoms of depression one year after the stroke (Visser-Meily *et al.*, 2008). Caregivers report significantly deteriorated quality of life, harmony in relationship and social relations in the period between one and three years after the stroke (Visser-Meily *et al.*, 2008). There is a growing tendency to shorten patients' admission time in hospitals and rehabilitation centers. As a result of this patients are discharged home earlier with more severe handicaps and needing more help in daily activities. Caregivers should be actively prepared on their future role during patients' rehabilitation (Wachters-Kaufmann *et al.*, 2005).

In the demanding process of rehabilitation after stroke social support is of great value to patients. Various studies found positive relationships between social support of stroke patients and improved functional status, improved quality of life (Gottlieb *et al.*, 2001), and less depression (Robinson *et al.*, 1999) Social support can be distinguished in emotional and instrumental support. In this, emotional support is described as comforting gestures, such as sharing ideas and experiences, or offering encouragement. It intends to alleviate uncertainty, anxiety, stress or depression. Instrumental support includes providing tangible goods such as physical care and services. Nurses have an important role in providing patients with social support by encouraging patients to use and enhance personal support networks (Fingeld-Connett, 2005).

One major component of stroke rehabilitation consists of exercise intervention to minimize the effect of the brain damage and optimize relearning. In a meta- analysis Kwakkel *et al.*

(2004) found that augmented exercise therapy has a small but favorable effect on ADL, particularly if therapy input is augmented at least 16 hours within the first 6 months after stroke. This meta-analysis also suggests that clinically relevant treatment effects may be achieved on instrumental ADL and gait speed. In a systematic review Rensink *et al.* (2009) identified task oriented training interventions which were highly relevant for nursing care and resulted in improved functional outcome and overall health related quality of life of patients with stroke. Nevertheless, stroke patients in various health care settings spent most of their time on non therapeutic activities and were found to be inactive and alone (Bernhardt *et al.*, 2004; De Wit *et al.*, 2005; Huijben-Schoenmakers *et al.*, 2009).

Involving caregivers in training activities is an appropriate way to increase the intensity of patients' therapeutic activities. Several studies described the effect of the involvement of caregivers on patient and caregiver outcomes. In four studies caregivers were trained in basic skills of moving and handling, facilitating activities of daily living and conducting simple care activities (Kalra *et al.*, 2004; Grasel *et al.*, 2005; McCullagh *et al.*, 2005; Ng *et al.*, 2005). All training programs included more training sessions (2-8 times), given individually or in groups. Practical skills training led to a decrease of burden in caregivers (Kalra *et al.*, 2004; McCullagh *et al.*, 2005; Ng *et al.*, 2005), less depression and better quality of life in both patients and caregivers (Kalra *et al.*, 2004) and improved functional outcomes (Ng *et al.*, 2005). One study focusing on training of care activities showed increased mobility, but no effects on psychosocial or other functional outcomes (Grasel *et al.*, 2005). However, the effect of these individual training components cannot be determined with certainty, because their characteristics differed and they were part of larger intervention programs. Caregiver training was found to reduce costs of stroke care, due to a higher proportion of patients achieving independence at an earlier stage (Patel *et al.*, 2004). Two studies aimed to achieve additional training activities for patients by involving caregivers in (group)exercises. The training was focused on muscle strength in the lower limb, stability and gait velocity and was supervised by physical therapists (Maeshima *et al.*, 2003; Galvin *et al.*, 2011). Functional outcomes increased in both studies, in one study patients' levels of integration in community increased and levels of caregiver strain decreased (Galvin *et al.*, 2011). Based on these outcomes it is recommended to apply additional exercising by involving caregivers to a wider range of activities, like activities of daily living. Nurses should supervise these training activities. The present study made a contribution to this purpose.

In the Netherlands recently a task oriented exercise program was developed. This training guide named Fast Forward includes various simple training exercises, aiming to use in daily care and to increase intensity of treatment without the need to enlarge rehabilitation teams (Willems, 2011). Fast Forward contains simple exercises focusing on ADL and mobility, with

emphasis on upper extremities, which can be practiced by the patient, possibly supported by a caregiver. The caregiver training of the patient using Fast Forward is supervised by nurses.

Prior to structural implementation of Fast Forward into the rehabilitation setting it was found important to investigate the feasibility and practicality of a nurse led intervention, where caregivers support patients doing the Fast Forward exercises. Feasibility is defined as the appropriateness of the intervention for the purpose being considered (Harris & Warren, 1995). This study focuses on the following aspects of feasibility: the availability of time, staff, knowledge and skills, equipment and facilities, the fit with the vision and the common methods on the ward (Burns & Grove, 2009). Patients, caregivers and nurses experiences with actively involving caregivers in exercising is investigated. Practicality is defined as the clinical utility of the intervention in the setting (Harris & Warren, 1995). Aspects of practicality are relevance, significance, workload, approval, clearness, quality of being user-friendly and complexity of the intervention (Burns & Grove, 2009).

Problem definition

Stroke is a complex disease which has huge consequences for patients and caregivers. Timely and intensive task oriented training for stroke survivors has positive effects on functional outcomes and overall health related quality of life, however stroke patients in various health care settings spend most of their time on non therapeutic activities. Involving caregivers in training programs may increase the intensity of exercising. Various studies have shown positive outcomes of involving caregivers in training patients with stroke, where it leads to a reduction of caregivers burden and may have positive effects on other psychosocial outcomes in both patients and caregivers. The training program Fast Forward was developed for self training activities. The feasibility and practicality of the Fast Forward nursing intervention, where caregivers are involved in the use of this training program along with patients, had not been investigated.

Aim

In order to increase the intensity of training activities of stroke patients by involving caregivers providing these activities, this study aimed to evaluate the feasibility and practicality of the training program Fast Forward where patients received simple exercises from caregivers under supervision of nurses on a stroke rehabilitation ward.

Research questions

- What is the feasibility and the practicality of the training program Fast Forward for *nurses* when caregivers provide the training?
- What is the practicality of the training program Fast Forward for *patients* when caregivers give simple exercises to patients?
- What is the practicality of the training program Fast Forward for *caregivers*, when they are involved in the use of it?

Methods

Design

A quantitative, descriptive design was used to evaluate the feasibility and practicality of Fast Forward as experienced by nurses, patients and caregivers. This is an appropriate design to give a description of concrete problems in practice (Burns & Grove, 2009). The study was approved by the Medical Ethics Committee of Rehabilitation Center 'De Hoogstraat' in Utrecht, the Netherlands.

Setting and subjects

The study was conducted on two stroke units (SU) of a rehabilitation center in the Netherlands, specialized in the rehabilitation of stroke survivors. The target population included nurses, stroke patients and their caregivers. It was estimated that all 23 nurses of the permanent staff would participate in the study. Based on previous numbers of admissions on the SU it was estimated that about 25 patients and their caregivers might be able to participate. Nurses were included if graduated at the level Bachelor of Science in Nursing (BSN), Licensed Practical Nurse (LPN) or Certified Nursing Assistant (CNA) and trained in using Fast Forward. Included were patients with the clinical diagnosis of stroke (cerebrovascular infarct or intracerebral hemorrhage) according to the definition of the WHO (World Health Organization, 1998), not suffering from severe cognitive impairments, having paresis in at least one arm or leg, Dutch speaking and having a caregiver. Caregivers were included who were either a partner or a close relation to the patient (daughter or son, parent, sibling), not suffering from severe cognitive or communicational impairments, aged over 20

years and Dutch speaking. The method of sampling was by convenience, using the most conveniently available people as study participants (Polit & Beck, 2008) (figure 1).

Intervention: Fast Forward

Fast Forward is an exercise program for self training activities for stroke patients and contains exercises for shoulder, head, neck, trunk, arm, hand and leg. One part of the program contains exercises on daily activities like brushing teeth, washing hands, opening and closing curtains. Presented as an exercise manual or a booklet the exercises are divided into three different color groups, depending on the severity of being affected: blue for patients with (almost) total paresis of arm or leg, green for patients with some function in arm or leg and orange for patients with (almost) total function in arm or leg. It also contains an explanation of the importance of exercising, a paragraph about safety, information for family caregivers and a list for recording time spent on exercising (Willems, 2011).

Patients receive the Fast Forward booklet from a physician or a nurse on the admission to the unit. The physical therapist and occupational therapist decide with the patient which exercises are to be used. This is noted in the patients' diary. In this way each patient receives a training program tailored to his needs. Patients receive Fast Forward-exercises in daily training groups. Besides, they are expected to practice independently. Exercises for the weekend, when most patients stay home, are assessed at Friday and evaluated at Monday in the Daily Orientation Group by a therapist and a nurse.

In this study, caregivers were involved in doing the Fast Forward-exercises with patients outside the therapeutic sessions under supervision of nurses. For nurses the application of the intervention not only included the use of the exercises but also the components: teaching and encouraging patients and caregivers to do the Fast Forward-exercises, explaining the importance of exercising, providing hands on training on how to do the exercises, answering questions and evaluating practice on the ward or at home during the weekend with patients and caregivers.

Data collection

An overview of data collection is given in figure 2.

Variables and instruments

Demographical characteristics

Nurses' demographic data collected using a questionnaire included age, sex, level of education, years of experience working in stroke rehabilitation and years working on the SU. Demographical characteristics of patients collected using nursing records included age, sex, marital status, level of education, time in days expired between stroke onset and date of inclusion, length of stay in rehabilitation center and discharge destination.

Demographical characteristics of caregivers, obtained using questionnaires, included age, sex and relationship to the patient.

Health-care characteristics of patients

All health-care characteristics of patients were obtained from the medical and nursing records. The clinical diagnosis of stroke and the type of stroke was provided by a neurologist and based on a CT-scan or an MRI. Information concerning motor function was divided into the categories right arm paresis, right leg paresis, left arm paresis and left leg paresis; sensory function disorder was distinguished in left arm, left leg, right arm and right leg. Information concerning language function was based on the diagnosis of a physician including motor aphasia, sensory aphasia or combined aphasia. The cognitive function was assessed by a physician, including mild or severe cognitive dysfunction. Functional status was measured using the modified Barthel Index Scale (BI). The BI is a 10 item instrument measuring disability in terms of a person's level of functional independence in personal activities of daily living (0=minimum independence, 20= maximum independence). The BI has been evaluated being a valid and reliable scale (Wolfe *et al.*,1991). The assessment of functional status was done by nurses within three days from admission.

Feasibility and practicality

Feasibility and practicality were evaluated using questionnaires focusing on the patients', caregivers' and nurses' experiences of using Fast Forward in the daily care of patients with stroke. The questions were based on a questionnaire of The Netherlands Centre of Excellence in Nursing (LEVV). The similar approach was used in a prior study by Vergunst

(not published) to evaluate the feasibility of a mobility intervention for stroke survivors, applied by caregivers. In that study the content validity of the questionnaires was judged by an expert panel.

Feasibility

Nurses. Concerning feasibility the questionnaire of nurses included 10 questions scored on a five point Likert scale ('disagree totally' to 'agree totally'). These questions focused on the following aspects: the availability of time, staff, knowledge and skills, materials and facilities, fit with the vision and the common methods on the ward (table 2). Two open questions followed concerning the amount of time nurses spent on learning and conducting the intervention. Nurses could explain the answers provided.

Practicality

Nurses. Concerning practicality the questionnaire of nurses included 13 questions, scored on a five point Likert ('disagree totally' to 'agree totally'), concerning relevance, workload, approval, quality of being user-friendly and complexity of the intervention (table 3). Then nurses were asked to express their experiences on the intervention using an open question and to assign a grade from one to 10 (one=very poor, 10=excellent) to the intervention. Nurses had the ability to describe commentary, suggestions and reactions concerning the intervention, given by patients and caregivers to nurses.

Patients. Patients were asked whether they exercised together with a caregiver. If they agreed five questions (five point Likert, 'disagree totally' to 'agree totally') on practicality were scored, focusing on significance, approval and burden of the intervention (table 3). Two open questions about their experience on the intervention and the amount of exercising they achieved a week followed. Finally they could assign a grade from one to 10 to the intervention.

Caregivers. Concerning practicality in caregivers the questionnaire included five questions (five point Likert scale), focusing on significance, approval and burden of the intervention (table 3). Caregivers were requested to express their experiences on training with the patient using one open question and to give a grade from one to 10 to the intervention.

The procedure of data collection

The Fast Forward program was implemented into daily care in October 2010. At the start of the study each nurse received an information letter on the ward and by e-mail including the aims and intervention protocol. Posters providing information about the study including the aims and the intervention protocol were displayed on both wards. A manual containing information on the study and the intervention protocol was available for information on each nursing ward. There was an information meeting with nurses and the researcher visited the wards on a regular basis to provide the nurses with information about the intervention and the study. All nurses of the permanent staff received an information letter on participation at the start and they received the questionnaire in the third last week of the study.

Stroke patients received the training guide Fast Forward when admitted on the wards. The first week after admission the researcher selected patients based on the inclusion criteria. Eligible patients were visited and informed about the study by the researcher. Interested patients received an information letter describing the Fast Forward intervention, and aims and procedure of the study and were asked to share this with their caregiver. One week later the researcher inquired if the patient and caregiver were willing to participate. If they agreed they received additional verbal information about the study and if they still agreed to participate they and the researcher signed a written consent form to participate in the study. In the second or third week prior to discharge patients and caregivers were interviewed separately using the questionnaires. The interviews took about 15 minutes. Data were collected from January – May 2011 (figure 2).

Data analysis

Descriptive statistics were used to calculate quantitative data. Data concerning feasibility and practicality were described by numbers and percentages. In demographic and health care characteristics discrete and categorical variables were described by numbers and percentages, continuous variables by means and standard deviation (sd). To compare means between groups the Shapiro-Wilk test of normality in small groups and the independent T-test for equality of means was used. Because the amount of exercising in patients who exercised with a caregiver was expected to increase, the level of significance was fixed on 0.05, one-sided, concerning the BI it was fixed on 0.05, two-sided. Analysis was conducted by SPSS16. The answers to open questions representing participants'

experiences were classified by identifying issues.

Results

Participants' characteristics

All nurses on the ward ($n=23$) were approached for participation. Of these 11 responded the questionnaire, showing a response rate of 47.8% (table 1).

A total of 34 eligible patients and their caregivers were approached for participation. Of these 13 (38.2%) couples agreed (figure 1). Of 13 participating couples six (46.2%) did the Fast Forward exercises together. The mean amount of exercising a week of patients who exercised with caregivers was 10.3 ($sd=5.09$), of patients who did not 6.1 ($sd=3.8$) (difference not significant, $p=.062$)(table 1).

Feasibility

Of 11 nurses eight (72.8%) agreed (totally) there was a fit with the vision on nursing care and the common methods on the ward, eight nurses (72.8%) disagreed they lacked materials and seven (63.7%) disagreed they lacked facilities to carry out the intervention. Seven nurses (63.7%) disagreed there was a lack of skills, six nurses (54.5%) disagreed (totally) there was a lack of knowledge, six (54.5%) thought staffing level was sufficient to apply the intervention. Four nurses (36.4%) disagreed there was sufficient time (table 2). The answers on the questions concerning time investment are represented in table 1.

Practicality

Nurses. Of 11 nurses 10 (90.9%) agreed (totally) the intervention was important in care for stroke patients and nine (81.8%) that the intervention had added value for the patient. Concerning approval to the intervention nine nurses (81.8%) agreed that the efforts outweighed the benefits and that the intervention fitted with what is important in nursing care and rehabilitation of patients with stroke. A number of 10 (90.9%) agreed there was a fit with what is important for caregivers. Nurses agreed (totally) the intervention was easy to apply ($n=8$, 72.7%) and easy to understand ($n=6$, 54.5%), seven nurses (63.7%) agreed (totally) the intervention was clear (table 3). The mean grade given to the intervention was 7,4.

Nurses' responses to the open question are represented in table 4.

Patients. Of six patients five (38.5%) agreed the intervention was valuable, six (46.2%) agreed it fitted their needs and four (30.8%) thought the intervention was important. Patients disagreed the intervention being burdensome for patient ($n=5, 38.5\%$) or caregiver ($n=4, 30.8\%$)(table 3). The mean grade given to exercising together was 7,8. The answers on open questions are represented in table 4.

Caregivers. All six caregivers agreed (totally) the intervention was valuable (46.2%), four (30.8%) thought it fitted their needs and was important. Caregivers disagreed (totally) the intervention was burdensome for them ($n=5, 46.2\%$), three (23.1%) disagreed (totally) the intervention was burdensome for the patient, three (23.1%) agreed with this (table 3). The mean grade given to the intervention was 7,7. The answers on open questions are represented in table 4.

Discussion

This study focused on the feasibility and practicality of a nursing intervention, where caregivers of stroke patients were involved in the training program Fast Forward. Nurses on a stroke rehabilitation ward were positive about the fit with the vision and common methods on the ward, the availability of staff, knowledge and skills, the importance in the care for stroke patients and their caregivers, and thought the efforts to apply the intervention outweighed the benefits. Patients and caregivers who performed the Fast Forward exercises together thought this was important, valuable and fitting their needs. The intensity of exercising among these patients probably increased.

Patients who did Fast Forward exercises together with a caregiver achieved a higher amount of exercising than patients who did not, although no significant difference was found. Additional exercising time was not measured, but may be considerable. In a study using an additional lower-limb family-mediated exercise intervention (FAME) for stroke patients on a rehabilitation unit a mean of 227 minutes (sd 34) additional therapy a week were measured (Galvin *et al.*, 2011). The outcomes on feasibility and practicality of Fast Forward were consistent with a study of Kalra *et al.* (2004) who found that training caregivers in basic care, moving, and handling and facilitation of activities of daily living is feasible during stroke rehabilitation. In that study patients' disability was not influenced by involvement of caregivers. Fast Forward aims to increase the intensity of several training activities outside therapeutic sessions as a result of which a positive effect on functional outcomes in patients may be expected (Maeshima *et al.*, 2003; Kwakkel *et al.*, 2004; Galvin *et al.*, 2011).The

findings also are important in relation to a better use of time, where various studies have shown that patients on stroke units spend most of their time in non-therapeutic activities (Bernhardt *et al.*, 2004; De Wit *et al.*, 2005).

Concerning practicality in patients the involvement of caregivers as experienced by patients was stimulating, motivating and satisfying. In this the concept of social support can be identified, as the patients were provided with support from their closed one's. The antecedents for social support are a need for social support, a social network and climate conducive to the process, the result is improved mental health (Finfgeld-Connett, 2005). Concerning the climate nurses may play an important role in creating the appropriate context by supporting patients and caregivers, giving them the skills and opportunities and make exercising with caregivers common use on the ward.

Caregivers were positive about their involvement in the training of patients, as it enabled them to contribute to the rehabilitation and to gain insight in functional status of the patient. Kalra *et al.* (2004) suggests that involvement in training programs may empower consenting caregivers in their future role by teaching them appropriate skills. In one study, which emphasizes the advantages of a family centered approach in stroke rehabilitation, practicing caregiver skills and involvement in therapy sessions is mentioned as a way to improve capacity of caregivers (Visser-Meily *et al.*, 2006).

Another important finding of the study was nurses' positive assessment of the intervention. Concerning the feasibility staffing level, knowledge and skills, facilities and materials were sufficient and the intervention fitted the vision on nursing care for stroke patients and common methods on the ward. Nurses' opinion on the availability of time varied, where 36.4% thought time to apply the intervention was insufficient. Concerning the practicality nurses thought the intervention was important in the care for stroke patients and had added value for the patient. They agreed there was a fit with what is important in the care for stroke patients and their caregivers and disagreed the intervention being complex. Interestingly, despite their positive evaluation of the intervention only a small number of nurses actually participated. For this several causes can be identified. First, it may be due to organizational circumstances. During the study a reorganization on the ward took place, being a serious limitation for the study. Nurses had to adjust their working routines to the new situation, remaining less time and attention for the intervention. Second, due to organizational reasons, no clinical lesson could be organized, which is found to be an appropriate strategy to implement a new intervention (Grol & Wensing, 2006). Furthermore, on the participating wards providing Fast Forward exercises and training to patients was generally seen as the role of therapists more than one of nurses. In a study on nursing perspective on the relationship between nursing and allied health in inpatient rehabilitation it

was found that, although nurses endorse teamwork meant working towards one major goal for the patient, nursing and allied health work in inpatient rehabilitation often was segregated (Pryor, 2008). In conclusion, considerable attention should be paid to the implementation of this nursing intervention using appropriate implementation strategies (Grol & Wensing, 2006). The implementation should not only focus on nurses' motivation, skills and knowledge but also on commitment on task and goal setting within the whole rehabilitation team.

It is recommended to conduct an effect study involving a larger sample, were intensity of training activities, functional outcomes in patients and psychosocial outcomes in patients and caregivers are evaluated (Polit & Beck, 2008).

Conclusion

Nurses were positive about the feasibility and practicality of a nursing intervention where caregivers were involved in training activities of stroke patients with stroke. Patients and caregivers who exercised together thought this was important, valuable and fitting their needs and patients probably accomplished a higher amount of training activities than patients who did the exercises on their own. Despite their positive assessment nurses showed little adherence to the intervention, which probably caused few patients and caregivers doing shared exercises. Considerable attention should be paid to the implementation of the intervention to make nurses actually perform it.

Relevance to clinical practice

Involving caregivers in training activities may be seen as an important way to increase the intensity of therapeutic activities in the rehabilitation of patients with stroke.

Strategies used for the implementation of the intervention in nursing teams should contain informative, motivating and educational elements but, moreover, should focus on commitment to goal and task setting within the whole rehabilitation team.

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References

- Bernhardt, J., Dewey, H., Thrift, A., & Donnan, G. (2004). Inactive and alone: physical activity within the first 14 days of acute stroke unit care. *Stroke; a Journal of Cerebral Circulation*, **35**, 1005-1009.
- Burns, N., & Grove, S. K. (Eds.). (2009). *The practice of nursing research: appraisal, synthesis and generation of evidence* (6th ed.). Saunders, Elsevier inc., St. Louis (US).
- De Wit, L., Putman, K., Dejaeger, E., Baert, I., Berman, P., Bogaerts, K., et al. (2005). Use of time by stroke patients: a comparison of four European rehabilitation centers. *Stroke; a Journal of Cerebral Circulation*, **36**, 1977-1983.
- Draper, P., & Brocklehurst, H. (2007). The impact of stroke on the well-being of the patient's spouse: an exploratory study. *Journal of Clinical Nursing*, **16**, 264-271.
- Finfgeld-Connett, D. (2005). Clarification of social support. *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, **37**, 4-9.
- Galvin, R., Cusack, T., O'Grady, E., Murphy, T. B., & Stokes, E. (2011). Family-mediated exercise intervention (FAME): evaluation of a novel form of exercise delivery after stroke. *Stroke; a Journal of Cerebral Circulation*, **42**, 681-686.
- Gottlieb, A., Golander, H., Bar-Tal, Y., & Gottlieb, D. (2001). The influence of social support and perceived control on handicap and quality of life after stroke. *Aging (Milan, Italy)*, **13**, 11-15.
- Grasel, E., Biehler, J., Schmidt, R., & Schupp, W. (2005). Intensification of the transition between inpatient neurological rehabilitation and home care of stroke patients.

Controlled clinical trial with follow-up assessment six months after discharge. *Clinical Rehabilitation*, **19**, 725-736.

Grol, R., & Wensing, M. (2006). *Implementatie: Effectieve verbetering van de patientenzorg* (3rd ed.). Elsevier Gezondheidszorg, Maarssen.

Hafsteinsdóttir, T., & Schuurmans, M. (2009). *Verpleegkundige revalidatierichtlijn beroerte* (1st ed.). Elsevier gezondheidszorg, Maarssen.

Harris, M. R., & Warren, J. J. (1995). Patient outcomes: assessment issues for the CNS. *Clinical Nurse Specialist CNS*, **9**, 82-86.

Hoeymans, N., Melse, J. M. & Schoemaker, C. G. (2010).
http://www.gezonderoudworden.nl/fileadmin/images/PDF/VTV_deelrapport_gezondheidsdeterminanten_2010_270061006.pdf (accessed 10 May 2011).

Huijben-Schoenmakers, M., Gamel, C., & Hafsteinsdottir, T. B. (2009). Filling up the hours: how do stroke patients on a rehabilitation nursing home spend the day? *Clinical Rehabilitation*, **23**, 1145-1150.

Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M., et al. (2004). Training care givers of stroke patients: Randomised controlled trial. *British Medical Journal*, **328**, 1099-1101.

Kwakkel, G., van Peppen, R., Wagenaar, R. C., Wood Dauphinee, S., Richards, C., Ashburn, A., et al. (2004). Effects of augmented exercise therapy time after stroke: a meta-analysis. *Stroke; a Journal of Cerebral Circulation*, **35**, 2529-2539.

Lloyd-Jones, D., Adams, R., Carnethon, M., De Simone, G., Ferguson, T. B., Flegal, K., et al. (2009). Heart disease and stroke statistics--2009 update: a report from the American

Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*, **119**, 480-486.

Maeshima, S., Ueyoshi, A., Osawa, A., Ishida, K., Kunimoto, K., Shimamoto, Y., et al. (2003). Mobility and muscle strength contralateral to hemiplegia from stroke: Benefit from self-training with family support. *American Journal of Physical Medicine and Rehabilitation*, **82**, 456-462.

McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke; a Journal of Cerebral Circulation*, **36**, 2181-2186.

Ng, S., Chu, M., Wu, A., & Cheung, P. (2005). Effectiveness of home-based occupational therapy for early discharged patients with stroke. *Hong Kong Journal of Occupational Therapy*, **15**, 27-36.

Patel, A., Knapp, M., Evans, A., Perez, I., & Kalra, L. (2004). Training care givers of stroke patients: economic evaluation. *BMJ (Clinical Research Ed.)*, **328**, 1102.

Polit, D. E., & Beck, C. T. (2008). *Nursing Research, Generating and Assessing Evidence for Nursing Practice* (8th ed.). Lippincott Williams & Wilkins, Philadelphia.

Pryor, J. (2008). A nursing perspective on the relationship between nursing and allied health in inpatient rehabilitation. *Disability and Rehabilitation*, **30**, 314-322.

Robinson, R. G. (2003). Poststroke depression: prevalence, diagnosis, treatment, and disease progression. *Biological Psychiatry*, **54**, 376-387.

Robinson, R. G., Murata, Y., & Shimoda, K. (1999). Dimensions of social impairment and their effect on depression and recovery following stroke. *International Psychogeriatrics / IPA*, **11**, 375-384.

- Teasell, R. W., Foley, N. C., Bhogal, S. K., & Speechley, M. R. (2003). An evidence-based review of stroke rehabilitation. *Topics in Stroke Rehabilitation*, **10**, 29-58.
- Van Exel, N. J. A., Koopmanschap, M. A., Van Den Berg, B., Brouwer, W. B. F., & Van Den Bos, G. A. M. (2005). Burden of informal caregiving for stroke patients: Identification of caregivers at risk of adverse health effects. *Cerebrovascular Diseases*, **19**, 11-17..
- Visser-Meily, A., Post, M., Gorter, J. W., Berlekom, S. B., Van Den Bos, T., & Lindeman, E. (2006). Rehabilitation of stroke patients needs a family-centred approach. *Disability and Rehabilitation*, **28**, 1557-1561.
- Visser-Meily, A., Post, M., van de Port, I., van Heugten, C., & van den Bos, T. (2008). Psychosocial functioning of spouses in the chronic phase after stroke: improvement or deterioration between 1 and 3 years after stroke? *Patient Education and Counseling*, **73**, 153-158.
- Wachters-Kaufmann, C., Schuling, J., The, H., & Meyboom-de Jong, B. (2005). Actual and desired information provision after a stroke. *Patient Education and Counseling*, **56**, 211-217.
- Willems, M. (2011). *Oefenboek Snel In Beweging*.
http://www.dehoogstraat.nl/onderzoeken/innovatie/snel_in_beweging (accessed 30 April 2011).
- Wolfe, C. D., Taub, N. A., Woodrow, E. J., & Burney, P. G. (1991). Assessment of scales of disability and handicap for stroke patients. *Stroke; a Journal of Cerebral Circulation*, **22**, 1242-1244.
- World Health Organisation. (1998). *World Health Report*. WHO, Genève.

Figure 1 Flow chart of the included patients

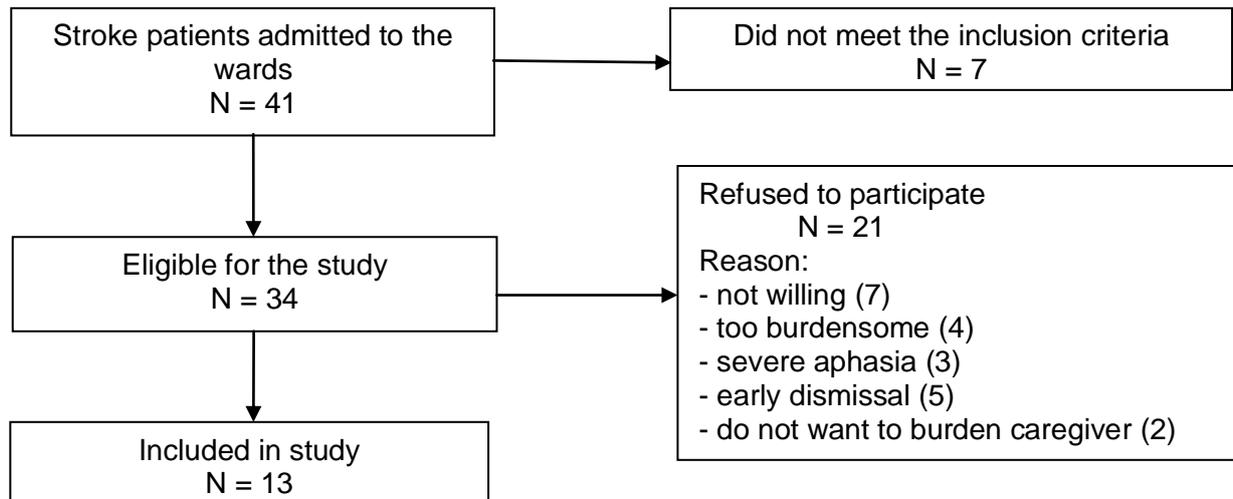


Figure 2 Scheme of data collection

Participant Data/time	Patient		Caregiver		Nurse	
Demographical characteristics (January-May)	- Age - Sex - Marital status - Level of education - Days expired between stroke onset and date of inclusion - Length of stay in RC - Discharge destination	Nursing and medical registers	- Age - Sex - Nature of relationship to patient	Questionnaires	- Age - Sex - Years of experience: - with stroke - on ward - Nursing education level - Way of getting informed	Questionnaires
Clinical characteristics (January - May)	- Motor function disorder - Sensory function disorder - Language function disorder - Functional status (BI)					
Feasibility Practicality Experiences 3th-2nd last week of study					Questionnaire	
Practicality Experiences 3th -2nd last week before dismissal	Questionnaire		Questionnaire			

Table 1 Demographical and health care characteristics participants

Variable	Outcome			
Nurses (n = 11)				
Mean (SD) age (years)		44.4 (11.0)		
Female (%)		9 (81.8%)		
Mean (SD) work experience SU(years)		13.4 (5.8)		
Mean (SD) working on ward (years)		12.0 (5.4)		
Highest completed nursing education:	BSN	3 (27.3%)		
	LPN	5 (45.5%)		
	CAN	3 (27.3%)		
Time spent on learning intervention	≤ 1 hour	9 (81.8%)		
	missing	2 (18.2%)		
Time spent conducting intervention	≥ 10 hours	1 (9.1%)		
	≤ 2 hours	1 (9.1%)		
	≤ 1 hour	3 (27.3%)		
	missing	6 (54.5%)		
Patients (n=13)				
		ET (n=6)	NET (n=7)	p-value
Mean (SD) age (years)		57.8 (11.7)	54.14 (12.8)	
Female (%)		4 (66.7%)	5 (71.4%)	
Marital status	married/cohabiting	5 (83.3%)	4 (57.1%)	
	living alone	1 (16.7%)	3 (42.9%)	
Level of education	elementary	2 (33.3%)	4 (57.1%)	
	secondary	1(16.7%)	1 (14.3%)	
	tertiary	2 (33.3%)	1 (14.3%)	
	higher	1(16.7%)	1 (14.3%)	
Clinical diagnosis: type of stroke	infarction	4 (66.7%)	6 (85.7%)	
	hemorrhage	2 (33.3%)	1 (14.3%)	
Mean (SD) interval stroke unset - date inclusion (days)		26.7 (18.9)	31.6 (8.1)	
Mean (SD) length of stay on SU (days)		75.5 (15.8)	72.1 (31.5)	
Discharge destination	home	5 (83.3%)	7 (100%)	
	nursing home	1 (16.7%)		
Motor function disorder	right arm paresis	2 (33.3%)	1 (14.3%)	
	right arm and leg	2 (33.3%)	3 (42.9%)	
	left arm and leg	1 (16.7%)	3 (42.9%)	
	tetraparesis	1 (16.7%)		
Sensory function disorder	right arm and leg	3 (50.0%)	1 (14.3%)	
	left arm and leg	1 (16.7%)	3 (42.9%)	
Language function	motor aphasia	2 (33.3%)	1 (14.3%)	
	combined aphasia	1(16.7%)	1 (14.3%)	
Mean (SD) BI admission		10.7 (6.3)	15.0 (4.7)	(p=.182)*
Amount of exercising/week		10.3 (5.09)	6.1 (3.8)	(p=.062)*
Caregivers (n = 12)				
		ET (n=6)	NET (n=6)	
Mean (SD) age (years)		47.2 (14.2)	52.3 (17.6)	
Female (%)		5 (83.3%)	4 (57.1%)	
Relationship to patient	spouse	4 (66.7%)	3 (42.9%)	
	parent	1 (16.7%)	1 (14.3%)	
	daughter	1 (16.7%)	1 (14.3%)	
	sibling		1 (14.3%)	
Values are numbers (percentages) of patients unless stated otherwise; ET= patients and caregivers who exercised together; NET= patients and caregivers who did not exercise together; BSN=Bachelor of Science in Nursing; LPN=Licensed Practical Nurse; CAN=Certified Nursing Assistant; BI= Barthel Index Scale 0-20 (low level=low level of function); * not significant (significance level: p≤0.05)				

Table 2 Feasibility of the Fast Forward program for nurses (n= 11)

Aspect of feasibility	Question	Disagree totally number(%)	Disagree number(%)	Agree nor disagree number(%)	Agree number(%)	Agree totally number(%)
Time	0 there is sufficient time to apply intervention		4 (36.4%)	4 (36.4%)	3 (27.3%)	
Staff	0 staffing level is sufficient to apply intervention		1 (9.1%)	4 (36.4%)	6 (54.5%)	
Knowledge and skills	0 instruction provides sufficient information to carry out intervention		1 (9.1%)	4 (36.4%)	6 (54.5%)	
	0 nurse lacks knowledge to carry out intervention	1 (9.1%)	5 (45.5%)	2 (18.2%)	1 (9.1%)	
	0 nurse lacks skills to carry out intervention		7 (63.7%)	2 (18.2%)	1 (9.1%)	
Materials and facilities	0 nurse lacks materials to carry out intervention		8 (72.8%)	3 (27.3%)		
	0 nurse lacks facilities to carry out intervention		7 (63.7%)	3 (27.3%)	1 (9.1%)	
Fits vision on the ward	0 background of intervention fits vision on nursing care			1 (9.1%)	8 (72.8%)	
	0 intervention fits usual care for patients with stroke		1 (9.1%)		8 (72.8%)	1 (9.1%)
Fits common methods on the ward	0 intervention is consistent with the routine of nursing care for patients with stroke		1 (9.1%)	1 (9.1%)	7 (63.7%)	1 (9.1%)

Table 3 Practicality of the Fast Forward program for nurses, patients and caregivers

Aspect of practicality	Question	Disagree totally number(%)	Disagree number(%)	Agree nor disagree number(%)	Agree number(%)	Agree totally number(%)
Nurses (n=11)						
Relevance	0 intervention is important in care for stroke patient				5 (45.5%)	5 (45.5%)
	0 intervention has added value for the patient			1 (9.1%)	6 (54.5%)	3 (27.3%)
	0 intervention provides new insights in nursing care for stroke patient			5 (45.5%)	4 (36.4%)	
Workload	0 intervention increases workload nurses		3 (27.3%)	5 (45.5%)	1 (9.1%)	1 (9.1%)
Approval	0 efforts of intervention outweigh the benefits			2 (18.2%)	9 (81.8%)	
	0 intervention fits with what is important in nursing care to patients with stroke			1 (9.1%)	9 (81.8%)	
	0 intervention fits with what is important for patient in rehabilitation			2 (18.2%)	9 (81.8%)	
	0 intervention fits with what is important for caregiver in rehabilitation			1 (9.1%)	10 (90.9%)	
Quality of being user-friendly	0 intervention protocol is easy to understand			4 (36.4%)	3 (27.3%)	3 (27.3%)
	0 description in the intervention protocol is clear			3 (27.3%)	5 (45.5%)	2 (18.2%)
Complexity	0 intervention is easy to apply			2 (18.2%)	6 (54.5%)	2 (18.2%)
	0 the components of the intervention follow each other logically			4 (36.4%)	4 (36.4%)	2 (18.2%)
	0 intervention is complex		6 (54.5%)	3 (27.3%)		
Patients (n=6)						
Significance	0 Intervention was important			2 (15.4%)	4 (30.8%)	
Approval	0 Intervention was valuable			1 (7.7%)	5 (38.5%)	
	0 intervention fits patients needs				6 (46.2%)	
Burden	0 intervention is burdensome for patient		5(38.5%)		1 (7.7%)	
	0 intervention is burdensome for caregiver		4 (30.8%)	1 (7.7%)	1 (7.7%)	
Caregivers (n=6)						
Significance	0 Intervention was important			2 (15.4%)	2 (15.4%)	2 (15.4%)
Approval	0 Intervention was valuable				4 (30.8%)	2 (15.4%)
	0 intervention fits needs caregiver		1 (7.7%)	1 (7.7%)	4 (30.8%)	
Burden	0 intervention is burdensome for patient	1 (7.7%)	2 (15.4%)		3 (23.1%)	
	0 intervention is burdensome for caregiver	1 (7.7%)	4 (38.5%)	1 (7.7%)		

Table 4 Practicality of the Fast Forward intervention for nurses, patients and caregivers: Issues from open questions

Issues	No. of times mentioned	Examples
Nurses (n=11)		
Increased amount of exercising	5	- intervention enables training activities seven days/week - intervention is consistent with evidence - intervention is consistent with guidelines stroke
Applicable soon after admission	2	- patients can start exercising soon after admission
Decreases inactive time	1	- patients fill up inactive moments by doing exercises
Involvement caregiver	1	- enables active contribution of caregiver
Social support	1	- it is a way to provide patient with social support
Self management	1	- it enables patients and caregivers to manage the process of rehabilitation themselves
Patients exercising with caregivers(n=6)		
Motivating, stimulating	5	- I'm very satisfied, the involvement of my partner motivated me - exercising together was stimulating
Caregivers exercising with patients (n=6)		
Importance	3	- my involvement was stimulating for my partner
	2	- it is a good intervention, I hope we can do if my father is in a nursing home - we started in hospital and continued here
Significance	3	- training together gave me satisfaction - it made possible to contribute to my husband's rehabilitation - involving caregivers sounds very positive to me
	2	- It made me see how burdening these simple exercises are for my mother - you can see where she has to work on - I saw which progress she made
Fast Forward, quality	3	- It's a good guidance