Towards improved multidisciplinary stroke care for older people

Assessing feasibility and effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients

Tom Vluggen

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Proefschrift

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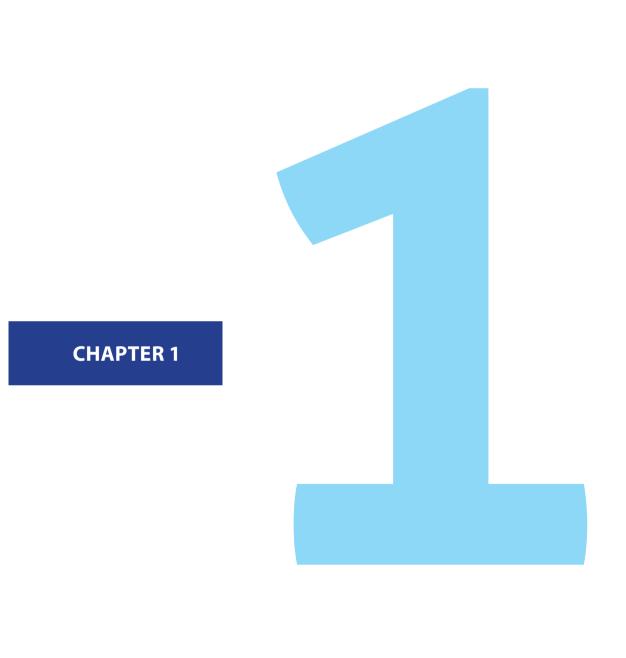
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Contents

CHAPTER 1

General introduction

Stroke among older people

Stroke is one of the major causes of loss of independence, decreased quality of life and mortality among the older population[1,2]. Each year, about 40,000 people in the Netherlands are affected by stroke and associated functional impairments[3]. Due to population ageing, the number of frail older patients with acute or chronic comorbidities is increasing[4]. Almost 56% of stroke patients are 65 years or older[5]. The prevalence of stroke among Dutch people of 65 years or older is estimated at 71 per 1,000 males and 54 per 1,000 females[3].

After admission to a hospital, about one third of older stroke patients is referred to an intermediate care facility for geriatric rehabilitation focusing in the rehabilitation of frail and multimorbid people[6-9]. Almost half of these older stroke patients has persisting mobility and ADL problems after rehabilitation discharge due to problems such as paresis, cognitive deficits, fatigue, behaviour problems and depression[10-14]. These problems may result in a decrease of the patient's functional level, increased social isolation and/or increased care dependency, which may even result in permanent admission to a nursing home[10-14]. Besides the negative impact of stroke on the patient, stroke can also have a negative impact on the care burden and quality of life of informal caregivers of patients[15,16]. These findings emphasize the importance of continuity of rehabilitation care for older stroke patients after discharge from inpatient geriatric rehabilitation.

Geriatric stroke rehabilitation in the Netherlands

In the Netherlands, geriatric rehabilitation facilities fulfil an important role in the rehabilitation of older community living stroke patients[8,17]. The main aim of this rehabilitation treatment is to restore independent functioning, enhance residual functional capacity in terms of mobility and activities of daily living, and to facilitate discharge to the former living situation[4,18-21].

Older community living stroke patients in general are admitted to a geriatric rehabilitation facility, when they are multimorbid, and cannot be directly discharged home from hospital due to the impact of stroke on their daily functioning, but are expected to be able to return home after completion of rehabilitation[6,22]

Patients in geriatric rehabilitation often show premorbid physical and cognitive impairments, a higher number of comorbidities and polypharmacy[21,23,24]. Because of their premorbid functional and cognitive status, older stroke patients often have limited exercise

tolerance and are cognitively more limited in (re)learning functional skills to restore independent functioning compared to younger patients. As a consequence, treatment intensity of geriatric rehabilitation is lower than specialised medical rehabilitation[25,26].

In the Netherlands, the care in specialised geriatric stroke rehabilitation units is provided by multidisciplinary teams and is coordinated by elderly care physicians[27]. An elderly care physician is a physician who is specialised in the care of frail and disabled older people with chronic and complex health problems[26,27]. The elderly care physician works interdisciplinary within a rehabilitation team which often consists of a physiotherapist, occupational therapist, speech therapist, dietician, and a (neuro)psychologist[9,26,27].

In general, the geriatric rehabilitation stroke unit offers a therapeutic environment to stimulate independent functioning and social participation. At admission to such a stroke unit, a treatment plan is developed, based on individual rehabilitation goals, which are formulated, by the patients in close collaboration with the stroke profession-als[26]. During rehabilitation, the main focus is on increasing the level of independent functioning and social participation. As soon as the rehabilitation goals are reached and the functional level has increased to an adequate level to ensure a safe return home, patients are discharged[26].

Need for adequate follow-up care after rehabilitation

At the start of our study in 2010, there was only limited attention for specialized aftercare in stroke rehabilitation to preserve the gains of inpatient geriatric rehabilitation and prevent functional decline of patients and its negative impact on informal caregivers[28]. This suggested the need to improve stroke rehabilitation by providing more specialized aftercare which includes effective methods to prevent or postpone functional decline after discharge and potentially avoidable permanent admissions to long term care facilities[29]. Furthermore, there was a need to identify predicting factors for home dis-charge after inpatient rehabilitation among frail and multimorbid older stroke patients, because it is important to support care professionals in making an adequate prognosis of discharge destination and in focusing their treatment on increasing the chances of home discharge.

However, at the start of our study there was no evidence based geriatric rehabilitation programme available for older stroke patients combining inpatient rehabilitation with adequate aftercare[28-44]. The evidence on effective aftercare was still limited and there was a need for more insight in the effectiveness of aftercare programs for older stroke patients and their informal caregivers[45,46].

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At the start of our study, research findings in the field of stroke aftercare indicated that adequate aftercare for the older population at least should include discharge follow up treatment in the patient's home environment, which facilitates early home discharge and improves the personal independence in daily living[29].

In addition, goal setting was considered an important aspect of adequate stroke (after) care[47,48]. Goal Attainment Scaling, which is a mathematical technique for quantifying the achievement of goals set in rehabilitation helps to use goal setting for research purposes.[47].

Goal Attainment Scaling (GAS) can also be applied to facilitate the training of patients with chronic conditions such as stroke patients in reaching a functional level during rehabilitation and preventing functional decline[48].

As mentioned above, to optimize the patient's functional performance level, research suggests that training sessions in the patients' home could be an effective approach to preserve and enhance the functional level as reached during inpatient rehabilitation[49,50]. Besides training the patient, it is also considered important to train informal caregivers in skills to assist the patient at home, and to support them in their role as informal caregivers and reduce their perceived care burden after home discharge[51]. Perceiving a high care burden is a very common problem in informal caregivers of stroke patients and needs specific attention in optimising the quality of life of informal caregivers[15,16].

Older stroke patients often have difficulties to remain socially active after discharge and have a higher risk of functional decline after discharge. Continuing rehabilitation in the home environment of the patient with involvement of the informal caregiver seems to contribute to preventing these problems[49,50]. Rehabilitation of the patient at home might increase the chance of preserving the functional capabilities of mobility and ADL activities such as walking, self-care and daily household tasks[49,50]. Furthermore, home therapy can also help facilitate earlier discharge to the patients home setting when the patient is still in the geriatric rehabilitation facility[49-51].

Next to formulating specific rehabilitation goals and home therapy, it seems important to increase problem solving skills of both stroke patients and informal caregivers by training and coaching them in self-management skills. This includes knowledge about the consequences of stroke, adaption to residual problems, and staying socially active with help from a stroke care professional [52,53]. In order to increase the knowledge about the consequences of stroke among patients and informal caregivers it is important to provide education in combination with coaching and support about stroke. In this way,

patients and informal caregivers gain more knowledge about the nature of the disease and the related problems such as cognitive and behavioural consequences, financial changes and changes in family roles. Information about these topics should be repeated more than once, and should be tuned to the demands of the individual patient and his or her informal caregivers[15,16].

Based on the promising program elements mentioned above (GAS, home therapy, self-management support and stroke education[15,16,25,30,48,52]) an integrated rehabilitation programme, specifically developed for older stroke patients and their informal caregivers, was developed and an outline is presented in the next paragraph.

An integrated rehabilitation programme for older stroke patients

As a response to the earlier mentioned need for adequate and continued follow-up care after inpatient geriatric rehabilitation, in 2010, Maastricht University in collaboration with six health care institutions, and primary care professionals have developed an integrated rehabilitation programme which aims to provide adequate care for older stroke patients and their informal caregivers who receive inpatient geriatric rehabilitation (immediately after the acute phase in hospital) and are discharged home (chronic phase after rehabilitation).

The rehabilitation programme includes elements to support patients to increase their level of daily activity, functional independence, perceived quality of life, and social participation sustainably[25]. In addition, the programme also aims to reduce the perceived burden of care and to increase the quality of life of the informal caregivers[25].

The specific content and important key elements of the geriatric rehabilitation programme are based on 1) evidence available from stroke research about inpatient rehabilitation and aftercare (including GAS, home therapy, self-management support, and stroke education) [16,17,48,52], and 2) expert knowledge from daily practice. To ensure centeredness on both patient and informal caregiver, during the design of the program, there was involvement of patients, informal caregivers, the Dutch Stroke Patient Association (Dutch: Nederlandse CVA-vereniging) and the Informal Caregivers Association (Dutch: Steunpunt Mantelzorger). To ensure successful development and implementation, a systematic approach and active participation of some geriatric rehabilitation facilities was required as well.

The development, implementation, and evaluation of the integrated rehabilitation programme for older people with stroke and their informal caregiver took place in the project 'MAESTRO; Multidisciplinary Aftercare for Elderly persons with STROke' (Dutch: 'Samen sterk na een beroerte'), which was part of the National Care for the Elderly Program[54], an initiative of and funded by The Dutch Organization for Health Research and Development (ZonMw) to improve the quality of care for frail older people.

The integrated rehabilitation programme consists of three complementary care modules: 1) inpatient neurorehabilitation treatment with goal setting by the Goal Attainment Scaling method; combined with two follow-up modules after discharge: 2) home based self-management training for patient and informal caregiver; and 3) stroke education with coaching and support for patient and informal caregiver. The intervention programme was delivered and evaluated on its effects in eight geriatric rehabilitation units in the South of the Netherlands.

Objectives of the study and outline of the dissertation

The studies presented in this dissertation had four main objectives. The first objective was to develop an integrated rehabilitation programme based on evidence from literature and in collaboration with stroke professionals in the field.

The second objective was to identify which factors were associated with home discharge after inpatient rehabilitation among frail and multimorbid older stroke patients.

The third objective was to evaluate the effects of the integrated rehabilitation programme on the level of daily activity, functional independence, perceived quality of life and social participation in older stroke patients as compared with usual stroke care and additionally on the perceived care burden and quality of life of the informal caregivers.

The fourth objective was to gain insight into the feasibility of the programme based on performance according to protocol, participation and opinions of patients, informal caregivers and stroke professionals.

The results of the different studies are described in five chapters.

In Chapter 2, a systematic literature review is presented, to provide insight in the effectiveness of multidisciplinary care for stroke patients living in the community and to identify elements to be used for development of the integrated geriatric rehabilitation

programme. Additionally, in Chapter 3, the results of a study to identify factors associated with successful home discharge after inpatient rehabilitation in frail older stroke patients are presented.

Chapter 4 describes the protocol of the MAESTRO study, which includes a description of the integrated geriatric rehabilitation programme for older people with stroke and the design of the multicentre randomized trial which evaluates the effects and feasibility of the new rehabilitation programme. Chapter 5 describes the effects of the programme as compared with usual stroke care on the primary outcome daily activity level, and on the secondary outcomes functional independence, perceived quality of life and social participation of patients. In addition the effects of the programme on the perceived care burden, objective care burden, and quality of life of the informal caregivers are also described in this chapter. Chapter 6 presents the results of the process evaluation which aims to gain insight in the feasibility of the programme by; 1) evaluating to what extent the integrated multidisciplinary rehabilitation programme was performed according to protocol; 2) evaluating the participation of the patients in the programme; and 3) assessing the opinion of patients, informal caregivers and care professionals on the programme.

The final chapter of this dissertation (general discussion) discusses and reflects on the main findings and implications of the integral study, together with its methodological strengths and limitations and provides recommendations for future practice and research.

References

1.   Lindsay MP, Norrving B, Sacco RL, Brainin M, Hacke W, Martins S, Pandian J, Feigin V. World Stroke Organization (WSO): Global Stroke Fact Sheet 2019. Int J Stroke. 2019 Oct;14(8):806-817.
2.   GBD 2016 Stroke Collaborators. Global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016 Lancet Neurol. 2019 May;18(5):439-458.
3.   Nivel Zorgregistraties eerste lijn 2018.
4.   Grund S, van Wijngaarden JP, Gordon AL, Schols JMGA, Bauer JM. EuGMS survey on structures of geriatric rehabilitation across Europe. Eur Geriatr Med. 2020 Apr;11(2):217-232.
5.   Gommer AM, Poos MJJC. Beroerte: prevalentie, incidentie en sterfte naar leeftijd en geslacht. Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM; 2011.
6.   Behandelkaders Geriatrische Revalidatie, Verenso 2017.
7.   Heijnen RW, Evers SM, van der Weijden TD, Limburg M, Schols JM. The cost effectiveness of an early transition from hospital to nursing home for stroke patients: design of a comparative study. BMC Public Health. 2010 May 26;10:279.

8. Inventarisatie zorginhoud GRZ. Het net opgehaald na zes jaar GRZ in de Zorgverzekeringswet. Q-Consult zorg. Utrecht februari 2019.

9. Achterberg WP, Cameron ID, Bauer JM, Schols JM. Geriatric Rehabilitation-State of the Art and Future Priorities. J Am Med Dir Assoc. 2019 Apr;20(4):396-398.

10. Norlander A, Carlstedt E, Jönsson AC, Lexell EM, Ståhl A, Lindgren A, Iwarsson S. Long-Term Predictors of Social and Leisure Activity 10 Years after Stroke. PLoS One. 2016 Feb 22;11(2):e0149395.

11. Dworzynski K, Ritchie G, Playford ED. Stroke rehabilitation: long-term rehabilitation after stroke.Clin Med (Lond). 2015 Oct;15(5):461-4.

12. Bachmann S, Finger C, Huss A, Egger M, Stuck AE, Clough-Gorr KM. Inpatient rehabilitation specifically designed for geriatric patients: systematic review and meta-analysis of randomised controlled trials. BMJ. 2010 Apr 20;340:c1718.

13. van Rijsbergen MWA, Mark RE, Kop WJ, de Kort PLM, Sitskoorn MM. Psychological factors and subjective cognitive complaints after stroke: Beyond depression and anxiety. Neuropsychol Rehabil. 2019 Dec;29(10):1671-1684.

14. Lo Coco D, Lopez G, Corrao S. Cognitive impairment and stroke in elderly patients. Vasc Health Risk Manag. 2016 Mar 24;12:105-16.

15. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: evidence-based clinical practice guidelines. J Rehabil Med. 2006;38(3):153–158.

16. Luker J, Murray C, Lynch E, Bernhardsson S, Shannon M, Bernhardt J. Carers' Experiences, Needs,and Preferences During Inpatient Stroke Rehabilitation: A Systematic Review of Qualitative Studies. Arch Phys Med Rehabil. 2017 Sep;98(9):1852-1862.e13.

17. Schols JMGA, Crebolder HFJM, Van Weel C. Nursing Home and Nursing Home Physician: The Dutch Experience. JAMDA. 2004;5(3):207–212.

18. Patrick L, Knoefel F, Gaskowski P, Rexroth D. Medical comorbidity and rehabilitation efficiency in geriatric inpatients. J Am Geriatr Soc. 2001 Nov;49(11):1471-7.

19. Quickscan Geriatrische revalidatiezorg, Eerstelijns Verblijf en Aanvullende Geneeskundige zorg. Q-Consult zorg. Utrecht mei 2019.

20. Grund S, Gordon AL, van Balen R, Bachmann S, Cherubini A, Landi F, Stuck AE, Becker C, Achterberg WP, Bauer JM, Schols JMGA. European consensus on core principles and future priorities for geriatric rehabilitation: consensus statement. Eur Geriatr Med. 2020 Apr;11(2):233-238.

21. Bachmann S, Finger C, Huss A, Egger M, Stuck AE, Clough-Gorr KM. Inpatient rehabilitation specifically designed for geriatric patients: systematic review and meta-analysis of randomised controlled trials. BMJ. 2010 Apr 20;340:c1718.

22. Zorgpad geriatrische revalidatiezorg. Academische werkplaats ouderenzorg Zuid-Limburg, Maastricht University. Maastricht, september 2017, versie 4.

23. Kus S, Müller M, Strobl R, Grill E. Patient goals in post-acute geriatric rehabilitation--goal attainment is an indicator for improved functioning. J Rehabil Med. 2011 Jan;43(2):156-61.

24. Wells JL, Seabrook JA, Stolee P, Borrie MJ, Knoefel F. State of the art in geriatric rehabilitation. Part I: review of frailty and comprehensive geriatric assessment. Arch Phys Med Rehabil. 2003 Jun;84(6):890-7.

25. Vluggen TP, van Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012 Dec 31;12:164.

26. Van Balen R, Gordon AL, Schols JMGA, Drewes YM, Achterberg WP. What is geriatric rehabilitation and how should it be organized? A Delphi study aimed at reaching European consensus. Eur Geriatr Med. 2019 10: 977–987.

27. Koopmans RT, Lavrijsen JC, Hoek JF, Went PB, Schols JM. Dutch elderly care physician: a new generation of nursing home physician specialists. J Am Geriatr Soc. 2010 Sep;58(9):1807-9.

28. Bollars S, van Erp J, Fens M, van Gorp E, van Hoppe J, Krikke T, de Meris, J, Notz B, van der Ven A, Vluggen T, Benjaminsen S: Uitbehandeld! Hoezo? Een leidraad in het doolhof van zorg in de chronische fase na een CVA. Kennisnetwerk CVA Nederland; 2012.

29. Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF: Therapy-based rehabilitation services for patients living at home more than one year after stroke. Cochrane Database Syst Rev 2008, 16(2):CD005952.

30. Fens M, Vluggen T, van Haastregt JC, Verbunt JA, Beusmans GH, van Heugten CM. Multidisciplinary care for stroke patients living in the community: a systematic review. J Rehabil Med. 2013 Apr;45(4):321-30.

31. Mulder AHM, De Witte LP, Diederick JPM. Evaluation of a rehabilitation after-care programme for stroke patients. Journal of Rehabilitation Sciences 1989;2(4):97–103.

32. Lincoln NB, Walker MF, Dixon A, Knights P. Evaluation of a multi-professional community stroke team: a randomized controlled trial. Clinical Rehabilitation 2004;18:40–7.

33. Allen KR, Hazelett S, Jarjoura D, Wickstrom GC, Hua K, Weinhardt J, Wright K. Effectiveness of a post-discharge care management model for stroke and transient ischemic attack. A randomised trial. J Stroke Cerebrovasc Dis 2002;11:88-98.

34. Allen K, Hazelett S, Jarjoura D, Hua K, Wright K, Weinhardt J, Kropp D. A randomised trial testing the superiority of a postdischarge care management model for stroke survivors. J Stroke Cerebrovasc Dis 2009;18:443-52.

35. Gladman JR, Lincoln NB. Follow-up of a controlled trial of domiciliary stroke rehabilitation (domino study). Age Ageing 1994;23:9-13.

36. Bjorkdahl A, Nilsson AL, Grimby G, Sunnerhagen KS. Does a short period of rehabilitation in the home setting facilitate functioning after stroke? A randomised controlled trial. Clin Rehab 2006;20:1038-49.

37. Burton C, Gibbon B. Expanding the role of the stroke nurse: A pragmatic clinical trial. J Adv Nurs 2005;52:640-50.

38. Forster A, Young J, Green J, Patterson C, Wanklyn P, Smith J, Murray J, Wild H, Bogle S, Lowson K. Structured re-assessment system at 6 months after a disabling stroke: A randomised controlled trial with resource use and cost study. Age Ageing 2009;38:576-83.

39. Gladman JR, Lincoln NB, Barer DH. A randomised controlled trial of domiciliary and hospital-based rehabilitation for stroke patients after discharge from hospital. J Neurol Neurosurg Psychiatry 1993;56:960-6.

40. Mayo NE, Nadeau L, Ahmed S, White C, Grad R, Huang A, Yaffe MJ, Wood-Dauphinee S. Bridging the gap: The effectiveness of teaming a stroke coordinator with patient's personal physician on the outcome of stroke. Age Ageing 2008;37:32-8.

41. Roderick P, Low J, Day R, Peasgood T, Mullee MA, Turnbull JC, Villar T, Raftery J. Stroke rehabilitation after hospital discharge: A randomized trial comparing domiciliary and day-hospital care. Age Ageing 2001;30:303-10.

42. Ryan T, Enderby P, Rigby AS. A randomised controlled trial to evaluate intensity of community-based rehabilitation provision following stroke or hip fracture in old age. Clin Rehab 2006;20:123-31.

43. Ytterberg C, Anderson Malm S, Britton M. How do stroke patients fare when discharged straight to their homes? A controlled study on the significance of hospital follow-up after one month. Scand J Rehabil Med 2000;32:93-6.

44. Markle-Reid M, Orridge C, Weir R, Browne G, Gafni A, Lewis M, Walsh M, Levy C, Daub S, Brien H, Roberts J, Thabane L. Interprofessional stroke rehabilitation for stroke survivors using home care. Can J Neurol Sci. 2011;38(2):317-34.

45. Shaw L, Bhattarai N, Cant R, Drummond A, Ford GA, Forster A, Francis R, Hills K, Howel D, Laverty AM, McKevitt C, McMeekin P, Price C, Stamp E, Stevens E, Vale L, Rodgers H. An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT. Health Technol Assess. 2020 May;24(24):1-202.

46. Rodgers H, Howel D, Bhattarai N, Cant R, Drummond A, Ford GA, Forster A, Francis R, Hills K, Laverty AM, McKevitt C, McMeekin P, Price CIM, Stamp E, Stevens E, Vale L, Shaw L. Evaluation of an Extended Stroke Rehabilitation Service (EXTRAS): A Randomized Controlled Trial and Economic Analysis. Stroke. 2019 Dec;50(12):3561-3568.

47. Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: a practical guide. Clin Rehabil. 2009 Apr;23(4):362-70.

48. Rockwood K, Stolee P, Fox R: Use of goal attainment scaling in measuring clinically important change in the frail elderly. J Clin Epidemiol 1993,46(10):1113–1118.

49. Fjaertoft H, Indredavik B, Lydersen S. Stroke unit care combined with early supported discharge: long-term follow-up of a randomized controlled trial. Stroke. 2003;34(11):2687–2691.

50. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database Syst Rev. 2003. p. CD002925.

51. Araújo O, Lage I, Cabrita J, Teixeira L. Training informal caregivers to care for older people after stroke: A quasi-experimental study. J Adv Nurs. 2018 May 12. doi: 10.1111/jan.13714.

52. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR: Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 2001,39(11):1217–1223.

53. Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? Disabil Rehabil. 2006;28(13–14):841–847.

54. ZonMw. Nationaal Programma Ouderenzorg (NPO): ZonMw; 2016 [26-10-2016]. Available from: http://www.beteroud.nl/ouderen/nationaal-programma-ouderenzorg-npo.html.

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CHAPTER 2

Multidisciplinary care for stroke patients living in the community: a systematic review

Objective
A systematic review of randomized controlled trials was performed to evaluate the effectiveness of multidisciplinary care for stroke patients living in the community.

Data sources
We used the databases Pubmed, Embase, Cinahl and Cochrane from January 1980 until July 2012.

Study selection
We selected randomized controlled trials focused on multidisciplinary interventions to stroke patients living at home after hospitalization or inpatient rehabilitation. The outcome domains were activities of daily living, social participation and quality of life. A total of 14 studies were included.

Data extraction
Two authors independently extracted the data and independently assessed the quality of reporting of the included studies using the CONSORT statement 2010.

Data synthesis
None studies showed a favourable effects of the intervention on activities of daily life and none studies have assessed social participation. Furthermore, two studies reported favourable effects of the intervention in terms of quality of life. These concerned an intervention combining assessment with follow-up care and a rehabilitation intervention.

Conclusions
There is little evidence for the effectiveness of multidisciplinary care for stroke patients being discharged home. Additional research should provide more insight into potentially effective multidisciplinary care for community-living stroke patients.

Keywords: review, stroke, ambulatory care, long-term care, quality of life, randomized controlled trial

Abstract

Introduction

Stroke is one of the major causes of mortality, loss of independence, and decreased quality of life.[1,2] Care for stroke patients is mostly concentrated in the acute and clinical phase, probably because most recovery occurs within this first period.[3] However, there is a considerable group of patients with persistent disabilities, even many years after stroke.[4-6] These disabilities can be physical limitations, such as paralysis or fatigue[7-9], but also psychological and cognitive problems, such as depression and memory deficits.[10-12] Many stroke survivors return to their former living environment, where they can be confronted with various difficulties in managing their daily activities and resuming their former social roles.[13,14] Patients have to learn how to deal with these difficulties for the rest of their lives and also learn how to socially reintegrate in the community. Although there seems to be a clear need for long-term care after being discharged home, adequate care is often lacking in this period.[15]

Previous research has indicated that organized inpatient care (stroke unit) is the health care model of choice within a hospital.[16] However, nowadays there is still a lack of insight into how other components of stroke care should be provided.[17] In particular, it is unclear how care should be organized after discharge from hospital or inpatient rehabilitation.[18-22] In the last ten years there have been several reviews of the effects of stroke care after discharge to the home situation, but these are dated[18,21], included cross-sectional studies and (non)-randomized trials[20], focused on a single discipline[22] or focused on more than a year post stroke.[19] A recent review of Hillier and Inglis-Jassiem[23] examined the effectiveness of stroke rehabilitation delivered at home or in an outpatient clinic for community-dwelling patients. This review showed that outpatient rehabilitation is more effective when it is provided in the patient's home. This study however concerned a specific comparison (i.e. home based versus clinic based care), and therefore there is still a need for additional insight into the effectiveness of other care programmes for stroke patients after discharge.

The present review aims to assess the effectiveness of different forms of multidisciplinary care delivered to stroke patients living in the community after discharge from hospital or inpatient rehabilitation. We reviewed the effectiveness of the interventions in terms of activities of daily living, social participation and quality of life, which we consider to be highly relevant outcome measures for stroke patients living in the community after discharge home.

Methods

A systematic literature review was performed using the following databases: Pubmed, Embase, Cinahl and the Cochrane library from January 1980 until July 2012. The search strategy, developed to identify the appropriate studies, comprised 4 categories: diagnosis; type of intervention; outcome; and setting (see online Appendix 1). The following inclusion criteria were used for the identified studies: randomized controlled trial; patients with a diagnosis of stroke; 18 years or older; community living after hospitalization or inpatient rehabilitation; multidisciplinary intervention; and outcome measures in the domains of activities of daily living, social participation and/or quality of life. We considered care to be multidisciplinary when care was provided by two or more different care professionals, working together as, or supported by, a team. Studies were excluded if the language was not English, Dutch or German. Furthermore, studies were excluded if the primary aim of the intervention was to reduce length of stay in hospital (i.e. early supported discharge).

Studies were independently selected by two reviewers (MF and TV) based on title and abstract and the selected articles were subsequently reviewed based on full text. Additional articles were tracked by hand search from the references of selected articles. In case of disagreement during the selection process, a third author (CvH) made the final decision. After the final selection, the two reviewers (MF and TV) extracted data independently and assessed the quality of reporting of the studies, using the CONSORT statement 2010.[24] The quality of the studies was indicated by the percentage of items of the CONSORT statement reported in the articles. Given the considerable heterogeneity of the interventions we decided not to statistically pool the data of the studies.

Results

Figure 1 shows the results of the selection process are shown. Out of 1,498 articles that were screened based on title and abstract, the two reviewer agreed on 1,425 articles and 73 articles were presented to the third reviewer A total of 95 articles and 5 additional articles found by hand search of references were read in full. The two reviewers reached consensus on 89 articles, 9 articles were presented to the third reviewer and two articles were untraceable. Fourteen articles were selected for the review [25-38] and 84 articles did not meet the inclusion criteria; no Randomized Controlled Trial (N=54), no stroke patients or community living patients (N=12), no multidisciplinary intervention (N=14), other outcome domains (N=3) and no English, Dutch or German (N=1). The selected 14 articles were published in English. Table 1 presents the characteristics of the included
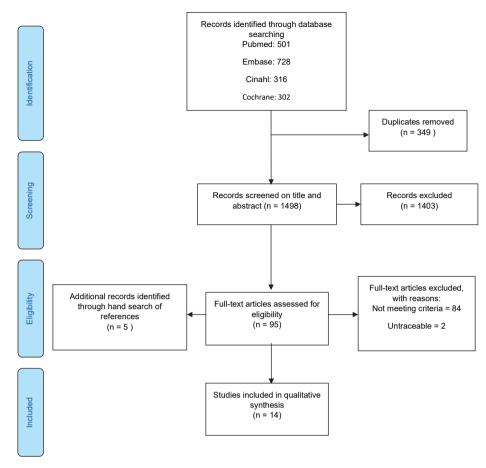
Fig 1. Selection process of the systematic review. From Moher D, Liberati A, Tetzlaff J, Altmann DG, The PRISMA group (2009). Preferred Reporting Items for Systematic Reviews and Meta- Analyses: The PRISMA Statemen. PLoS Med 6(6):e1000097. Doi: 10.1371/journal.pmed1000097. For more in-formation, visit www.prisma-statement.org.

studies and table 2 presents the characteristics of the interventions assessed in these studies.

Study design

Table 1 shows that 13 studies compared an intervention with usual care and one study compared intensive with non-intensive home-based rehabilitation[37]. The content of the interventions will be discussed in more detail below. The definition of usual care differed considerably between studies, such as outpatient rehabilitation at a day clinic, inpatient case management, care from a general practitioner, home care services with non-professional support or a service information pack. In 12 studies patients were

Table 1: Study characteristics of studies included in the systematic review

Study & country	Sample size (E/C)	Mean age & Male (N/%)	Type and severity of stroke	Intervention	Follow-up outcome	Outcome measures of interest and effects (E:score/ C:score)[a]	Effect for experimental group[b]
Allen et al. (2002)[25] USA	E:47 C:46	70.5 yrs. 43 (46%)	Ischaemic stroke and TIA, Rankin scale ≤ 3	Postdischarge care management vs regular care physician	Post-intervention	BI: E:95 (SD -), C:95 (SD -) (NS)	0
						SA-SIP30: E:0.8 (SD -), C:0.71 (SD -) (S)	+
Allen et al. (2009)[26] USA	E:190 C:190	68.5 yrs. 190 (50%)	Ischaemic stroke, NIHSS ≥1	Postdischarge care management vs regular care physician	Post-intervention	SSQoL: E:196 (SD-), C:199 (SD -) (NS)	0
Bjorkdahl et al. (2006)[27] Sweden	E:30 C:29	53 yrs. median 44 (75%)	Ischaemic stroke or Haemorrhage, Not described	Individual tailored-training by PT and OT	Post-intervention, 2 and 11 months after intervention	*Post-intervention:*	
						AMPS motor: E:1.71 (SD 0.91), C:1.52 (SD 0.71) (NS)	0
						AMPS Process: E:1.26 (SD 0.75), C:1.37 (SD 0.53) (NS)	0
						FIM motor E:2.83 (SD 2.05), C:2.38 (SD 1.7) (NS)	0
						FIM social E:2.62 (SD 1.85), C:2.94 (SD1.57) (NS)	0
						IAM E:0.29 (SD 1.35), C:0.08 (SD 0.99) (NS)	0
						2 months:	
						AMPS motor E:2.02 (SD 1.08), C:1.88 (SD 0.78) (NS)	0
						AMPS process E:1.23 (SD 0.64) C:1.54 (SD 0.53) (NS)	0
						FIM motor E:3.22 (SD 2.12), C:2.86 (SD 1.9) (NS)	0
						FIM social E:2.65 (SD 1.7), C:3.04 (SD 1.48) (NS)	0
						IAM E:0.54 (SD 1.47), C:0.59 (SD 1.2) (NS)	0
						11 months:	
						AMPS motor E:2.18 (SD 1.04), C:2.28 (SD0.94) (NS)	0
						AMPS process E:1.55 (SD 0.76), C:1.59 (SD0.68) (NS)	0
						FIM motor E:3.14 (SD 2.07), C:2.99 (SD 1.76) (NS)	0
						FIM social E:2.68 (SD 1.67), C:3.29 (SD 1.5) (NS)	0
						IAM E:0.7 (SD1.63), C:1.05 (SD 1.76) (NS)	0

Table 1: Study characteristics of studies included in the systematic review *(continued)*

Study & country	Sample size (E/C)	Mean age & Male (N/%)	Type and severity of stroke	Intervention	Follow-up outcome	Outcome measures of interest and effects (E:score/ C:score)[a]	Effect for experimental group[b]
Burton et al. (2005)[28] UK	E:87 C:89	75.2 yrs. 92 (52%)	Not described	Nurse follow-up vs usual care	1 and 10 months post intervention	*1 months:* BI: E:15 (IQ 11), C:14 (IQ 8.5) (NS) FAI: E:7 (IQ 14), C:7 (IQ 15) (NS) *10 months:* BI: E:17 (IQ 10), C:13.5 (IQ 7.25) (NS) FAI: E:14 (IQ 16.3), C:12 (IQ 19.5) (NS)	0 0 0 0
Forster et al. (2009)[29] UK	E:132 C:133	77/79 yrs. median 121 (46%)	Ischaemic stroke or Haemorrhage , Not described	Structured assessment system vs existing care	6-7 months post-intervention	FAI: E:6 (IQR 2-18), C:4 (IQR 1-14) (NS) BI: E:16 (IQR 12-18), C:16 (IQR 11-18) (NS)	0 0
Gladman et al. (1993)[30] UK	E:162 C:165	70 yrs. 173 (53%)	Not described	Domiciliary service vs usual practice	Post-intervention	BI: E:17 (IQR 14-19), C:18 (IQR 15-20) (NS) Extended ADL: E:8.5 (IQR 4-14), C:8 (IQR 4-14) (NS)	0 0
Gladman et al. (1994)[31] UK			Not described		Post-intervention and 6 months post intervention	*6 months:* BI: E:17 (SD -), C:18 (SD -) (NS) Extended ADL: E:8 (SD -) C:10 (SD -) (NS)	0 0
Lincoln et al. (2004)[32] UK	E:189 C:232	72 yrs. 222 (53%)	Not described	Community-stroke team vs routine care	Post -intervention	BI: E:16 (IQR 12-18), C:16 (IQR 12-19) (NS) Extended ADL: E:24 (IQR 13-38), C:25.5 (IQR 11-39) (NS) EQ-5D: E:52 (IQR 41-78), C:55 (IQR 40-72) (NS)	0 0 0
Markle- Reid et al. (2011)[33] Canada	E:43 C:39	73 yrs. 45 (37%)	Not described	Specialized interprofessional team vs usual home care services	Post -intervention	SF-36 physical functioning: E: 28.84 (SD 30.68) / C : 28.85 (SD 28.48) (NS) SF-36 social functioning: E: 66.57 (SD 34.69) / C :59.29 (SD 30.71) (NS)	0 0

Table 1: Study characteristics of studies included in the systematic review *(continued)*

Study & country	Sample size (E/C)	Mean age & Male (N/%)	Type and severity of stroke	Intervention	Follow-up outcome	Outcome measures of interest and effects (E:score/ C:score)[a]	Effect for experimental group[b]
Mayo et al. (2008)[34] Canada	E:96 C:94	71 yrs. 116 (61%)	Not described, CNS <6	Case-management vs usual care	post-intervention and 4,5 months after intervention	*Post intervention:* PCS: E: 40 (SD 1.3) C: 38.4 (SD 1.4) (NS)	0
						MCS: E:6.4 (SD 1.4), C:45.6 (SD 1.4) (NS)	0
						EQ-5D: E:0.63 (SD 0.02), C:0.62)(SD 0.02) (NS)	0
						BI: E:91.4 (SD 2.1), C:90.4 (SD 1.7) (NS)	0
						4,5 months:	
						PCS: E:43.4 (SD 1.4), C:40.1 (SD 1.5) (NS)	0
						MCS: E:50.6 (SD 1.3) C:48.2 (SD 1.5 (NS)	0
						EQ-5D: E:0.69 (SD 0.02), C:0.64 (SD 0.03) (NS)	0
						BI: E:92.7 (SD 2.0), C:89.9 (SD 2.2 (NS)	0
Mulders et al. (1989)[35] Netherlands	E:38 C:18	56.8 yrs. 30 (53,6%)	Not described	Rehabilitation programme vs usual care	6 months post intervention	SIP: E:22.7 (SD -) C:17.5 (SD -) (NS)	0
Roderick et al. (2001)[36] UK	E:66 C:74	79 yrs. 65 (46%)	Not described, BI <10	Domiciliary stroke team vs multi-disciplinary team	6 months post discharge	BI: E: 17 (IQR 10.8 – 19), C:15.5 (IQR 9-18) (NS)	0
						FAI: E:12 (IQR 3-25.3), C:7.5 (IQR 3-16.5) (NS)	0
						SF-36:	
						- physical functioning: E:35.2 (IQR 26.5-43.7), C:32.7 (IQR 26.8 – 39.2) (NS)	0
						- mental functioning: E:57.4 (IQR 49.9 – 62.9), C:57.1 (IQR 50.6 – 63) (NS)	0
Ryan et al. (2006)[37] UK	E:45 C:44	76,8 yrs. Not described	Not described, BI	Intensive vs non-intensive home-based rehabilitation	Post intervention	BI: E:19 (IQR 17-20), C:18,5 (IQR 17-20) (NS)	0
						EQ-5D: E:0.71 (IQR 0.59 – 0.81), C:0.54 (IQR 0.26 – 0.73) (S)	+
						FAI: E:14 (IQR 6-26), C:18 (IQR 6-24) (NS)	0
Ytterberg et al. (2000)[38] Sweden	E:56 C:55	73.5 yrs. 57 (51%)	Not described	Follow-up-visits vs usual care	2 months post intervention	Katz ADL index E:100% (SD -) C:98% (SD -) (NS)	0

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[a] The outcome measure is presented, followed by the mean score of the experimental group(s), the mean score of the control group and the difference between groups in terms of (non)significant.

[b] 0, no differences between groups; +, positive effect for experimental group; -, negative effect for experimental group

E: experimental group; C, control group; N, number of patients; IQR interquartile range; TIA: transient ischaemic attack; BI, Barthel Index; SA-SIP30, Stroke Adapted-Sickness Impact Profile 30; NHSS: National Institutes of Health Stroke Scale; SSQoL: Stroke Specific Quality of Life Scale; PT: physiotherapist; OT: occupational therapist; AMPS: Assessment of Motor and Process Skills; FIM: Functional Independence Measure; IAM: Instrumental Activity Measure; FAI: Frenchay Activities Index; extended ADL: extended Activities of Daily Living; EQ-5D: EuroQol-5D; SF-36: Short Form 36; CNS: Canadian Neurological Scale; PCS: Physical Component Summary; MCS: Mental Component Summary, SIP: Sickness Impact Profile; Katz ADL index: Katz Activities of Daily Living index; NS: not significant, S: significant; SD standard deviation.

included immediately after discharge home from hospital, in one trial patients were included ≥18 months post stroke[33] and in another trial patients were included after discharge from a rehabilitation center[35]. The period between stroke occurrence and discharge was described by only 3 out of 14 studies[29,35,37], varying from an average of 45 days[37] to 2.5 years[33].

Patient characteristics

The number of stroke patients in the intervention groups varied from 30[27] to 190.[26] The mean age of patients was under 70 years in 3 studies[26,27,35] and over 70 years in 11 studies. In general, men and women were equally represented in each of the studies; however in 1 study there were considerably more men (75%) in the study group[27].

Description of intervention

Table 2 shows that the 14 interventions differed in terms of organization, disciplines involved, duration and intensity. Four main types of interventions could be identified: assessment (N=2); assessment combined with follow-up care (N=8); rehabilitation (N=3); and education (N=1).

The first type of intervention (assessment) consisted of a single visit at home or at a clinic which aimed to prevent a negative course of events.[29,38] The assessments were performed by a multidisciplinary team[38], consisting of a physiotherapist, occupational therapist, counsellor and doctor, or a nurse with a consultant multidisciplinary team or with links to social services.[29] The assessments were performed at 1 month[37] or 5-6 months after discharge home.[29]

The second type of intervention (assessment combined with follow-up care) could be subdivided into assessment with either subsequent follow-up visits (N=5) [25,26,28,33,34] or assessment with subsequent rehabilitation (N=3).[30-32] The 5 assessments with follow-up visits were aimed at coping with the consequences of stroke[28] and improving the quality of life[33,34]. Nurses performed the assessment and follow-up visits and consulted with the patient's physician[34] or a multidisciplinary team.[25,26,28,33]. There was considerable variation in the duration of assessment and follow-up visits, varying from 6 weeks[34] to 12 months[26,33]. The 3 assessments performed with subsequent rehabilitation were focused on improving functional abilities of stroke patients.[30-32] The interventions were provided by a physiotherapist and occupational therapist[30,31], who could work together with a speech therapist and a nurse[32]. They provided therapy for a period of six months[30,31] or as long as needed[32]. The third type of intervention (rehabilitation) aimed to improve functional outcome and skills and involved disciplines such as physiotherapists, occupational therapists, physicians and speech therapists.[27,35,36]. The duration of the programme varied between three weeks[27] to as long as needed[35], as well as varying in intensity. All interventions were performed at the patient's home. The fourth type of interven-

Table 2: Intervention characteristics of studies included in the systematic review

Study & Country	Aim of intervention	Intervention	Disciplines involved	Start intervention & duration	Control
Allen et al. (2002)[25] USA	Not described	Postdischarge care management in which nurses performs home assessment, consult with interdisciplinary team and follow-up visits if necessary	Nurse, internist, physiotherapist & geriatric	After discharge 3 months	Usual care from physician
Allen et al. (2009)[26] USA				After discharge 6 months	
Bjorkdahl et al. (2006)[27] Sweden	To give support, info and training at home to transfer skills achieved in hospital into the home environment	Individually tailored training based on patient's needs in home setting.	physiotherapist & occupational therapist	After discharge 9 h/week for three weeks	Ordinary outpatient rehabilitation - a multiprofessional team offered training of deficits and functioning at a day clinic
Burton et al. (2005)[28] UK	To promote coping and adaptation to the consequences of stroke	Usual follow up care (liaison with general practitioner, outpatient follow-up and access to multi-professional rehabilitation services) + inpatient nurse assessment of recovery and follow-up visits of nurse at home	Nurse cooperating with physiotherapist, occupational therapist & community psychiatric nurse	After discharge 3 times in 2 months	Usual follow care + standard care – inpatient case management by stroke nurse
Forster et al. (2009)[29] UK	Not described	Existing care supplemented with structured assessment at 5-6 months post stroke onset by a nurse and multidisciplinary team or only nurse	Nurse and multidisciplinary team (team members are not described)	After discharge At 5-6 months	Existing care arrangement and a service information pack

Table 2: Intervention characteristics of studies included in the systematic review *(continued)*

Study & Country	Aim of intervention	Intervention	Disciplines involved	Start intervention & duration	Control
Gladman et al (1993)[30] UK Gladman et al. (1994)[31] UK	Domiciliary service improves functional independence	Domiciliary service with assessment and adequate help	Physiotherapist and occupational therapist	After discharge 6 months post discharge	Usual practice – day hospital or outpatient physiotherapy or occupational therapy
Lincoln et al. (2004)[32] UK	Rehabilitation by specialist multi-professional team improves functional abilities, mood, QoL and satisfaction with care	Community-stroke team with assessment, discussion and therapy	Occupational therapist, physiotherapist, speech therapist and nurse	Not described One visit and then as long as needed	Routine care - day hospitals, outpatients departments and social services occupational therapy
Markle-Reid et al. (2011)[33] Canada	To improve health related quality of life, physical functioning, perceived social support, depressive and anxiety symptoms, number of strokes, cognitive function and the level of community reintegration	Interprofessional rehabilitation programme of 12 months with home visits and an individualised care plan	Care coordinator, nurse, physiotherapist, occupational therapist, speech language pathologist, dietitian, social worker and personal support worker	≤18 months post-stroke 12 months	Usual home care services – routine follow-up by care coordinator in collaboration with multidisciplinary team and non-professional support services
Mayo et al. (2008)[34] Canada	To improve the health-related quality of life and decrease ER visits and non elective hospitalizations	Case-management by nurses home visits and interventions	Nurse (and personal physician)	After discharge 6 weeks	Usual care - appointment with their physician or local community health centre
Mulders et al. (1989)[35] Netherlands	To positively influence active recreation and pastime and stimulate social contacts after clinical rehabilitation	Rehabilitation programme of exercises, discussion and information-education	Physiotherapist and occupational therapist	Not described 22 meetings of 2,5 hours in 1 year	Usual care

2

Table 2: Intervention characteristics of studies included in the systematic review *(continued)*

Study & Country	Aim of intervention	Intervention	Disciplines involved	Start intervention & duration	Control
Roderick et al. (2001)[36] UK	Not described	Domiciliary stroke team planning activities using goal-setting approach	Physiotherapist, occupational therapist an geriatrician	Not described Until maximum recovery	Usual day hospital rehabilitation - individual of group care by a multi-disciplinary team
Ryan et al. (2006)[37] UK	Not described	Intensive home-based rehabilitation of 6 or more contacts per week with a local multidisciplinary team	Physiotherapist, occupational therapist, speech therapist & therapy assistant	After discharge Max 12 weeks	Non-intensive home based rehabilitation of 3 or less contacts per week with a local multidisciplinary team
Ytterberg et al. (2000)[38] Sweden	Preventing a negative course of events by means of follow-up visits	One time all-day follow-up visit after discharge	Counsellor, physiotherapist, occupational therapist and nurse, doctor	After discharge 1 month	Usual care from general practitioner

tion (education) aimed to stimulate social contacts and active recreation.[34] Patients participated in group discussions about current events and in outdoor activities such as dining and going to the theatre. The intervention was performed by physiotherapists and occupational therapists, providing education and information 22 times in 1 year. Ten interventions started directly after discharge home from hospital and 1 intervention started within 18 months post-stroke[33]. For the other three interventions it was unclear when the interventions started[32,35,36].

Outcome measures and effects

Eleven studies assessed activities of daily living using the Barthel Index (N=9), Frenchay Activities Index (N=4), extended Activities of Daily Activities (N=3), Functional Independence Measure (N=1), Instrumental Activity Measure (N=1), Assessment of Motor and Process Skills (N=1), Mental Component Summary/Physical Component Summary (N=1), and Katz Index (N=1)[25,27-32,34,36-38]. None of these studies found an effect of the intervention on daily activities. Social participation was assessed in none of the studies. Eight studies assessed quality of life, using the Euroqol-5D (N=3), Stroke Adapted-Sickness Impact Profile 30 (N=1), Short Form 36 (N=2), Stroke Specific Quality of Life Scale (N=1) and/or Sickness Impact Profile (N=1)[25,26,32-37] Out of these 8 studies, the studies of Allen et al.[25] and Ryan et al.[37] reported favourable effects of the intervention on quality of life. In the study of Allen et al.[25] (assessment with follow-up care), an advanced practice nurse care manager performed a telephone assessment 3-7 days after discharge home and provided some education. A month later the advanced nurse visited patients at home for a standardized biopsychosocial assessment for stroke-specific problems. The findings of this assessment were discussed by the post-stroke consultation team to develop an individual care plan. Three months after discharge home, patients receiving the intervention reported an increased quality of life, using a stroke adapted outcome measure (SA-SIP30). In the study of Ryan et al.[37], (rehabilitation) a multidisciplinary team provided 6 or more face-to-face contacts a week.

During these contacts, patients received therapy for a maximum period of 12 weeks, which was compared with a control group receiving 3 or less face-to-face contacts a week. None of the patients needed 12 weeks of therapy. The patients receiving 6 or more face-to-face contacts a week reported a better quality of life than patients who received 3 or less face-to-face contacts a week.

Quality of reporting of the study

The percentage of the CONSORT items reported in the included studies ranged from 35% to 73%, with a mean of 55% (table 3). The study of Markle-Reid et al.[33] had the highest quality (73%), while the study of Ytterberg[38] had the lowest quality (35%). The CONSORT statement can be divided into 7 categories: "title/abstract"; "introduction";

Table 3: Quality assessment of included studies using the Consort statement 2010

	Allen et al. 2002[25]	Allen et al. 2009[26]	Bjorkdahl et al. 2006[27]	Burton et al. 2005[28]	Forster et al. 2009[29]	Gladman et al. 1993[30]	Gladman et al. 1994[31]	Lincoln et al. 2004[32]	Markle-Reid et al. 2011[33]	Mayo et al. 2008[34]	Mulders et al. 1989[35]	Roderick et al. 2001[36]	Ryan et al. 2006[37]	Ytterberg et al. 2000[38]	Total category (%)
Title, Abstract															
RCT in title	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	No	
Structured summary	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	
(max. 2)	2	2	2	1	2	2	2	2	1	1	1	2	2	0	**22 (79%)**
Introduction															
Background scientific	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Hypothesis	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
(max. 2)	1	1	2	2	2	2	2	2	2	2	2	2	2	2	**26 (93%)**
Methods-trial															
Description trial design	No	No	No	Yes	No	No	Yes	No	Yes	Yes	Yes	No	No	No	
Changes trial design	No	No	No	No	No	No	No	Yes	No	No	No	No	No	No	
Eligibility criteria	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Setting and location	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	No	No	
Description intervention	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	
Description outcomes	No	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	

Table 3: Quality assessment of included studies using the Consort statement 2010 (continued)

	Allen et al. 2002[25]	Allen et al. 2009[26]	Bjorkdahl et al. 2006[27]	Burton et al. 2005[28]	Forster et al. 2009[29]	Gladman et al. 1993[30]	Gladman et al. 1994[31]	Lincoln et al. 2004[32]	Markle-Reid et al. 2011[33]	Mayo et al. 2008[34]	Mulders et al. 1989[35]	Roderick et al. 2001[36]	Ryan et al. 2006[37]	Ytterberg et al. 2000[38]	**Total category (%)**
Changes outcome	No	No	No	No	No	No	No	No	No	No	No	No	No	No	
Sample size	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	Yes	Yes	No	
Interim analysis / stopping guidelines	No	No	No	Yes	No	No	No	No	No	No	No	No	No	No	
(max. 9)	4	4	5	6	4	5	5	5	6	5	3	4	4	2	**62 (49%)**
Method-randomisation															
Method randomiza-tion	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	No	Yes	Yes	Yes	No	
Type of randomisa-tion	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	
Allocation conceal-ment	Yes	Yes	No	No	No	Yes	No	No	Yes	Yes	No	No	Yes	No	
Implemen-tation	No	No	No	No	No	No	No	Yes	Yes	Yes	No	Yes	Yes	No	
Blinding	No	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	No	No	Yes	No	
Similarity intervention	No	No	Yes	No	No	No	No	No	No	No	No	No	No	No	
Statistics group measures	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	

Table 3: Quality assessment of included studies using the Consort statement 2010 *(continued)*

	Allen et al. 2002[25]	Allen et al. 2009[26]	Bjorkdahl et al. 2006[27]	Burton et al. 2005[28]	Forster et al. 2009[29]	Gladman et al. 1993[30]	Gladman et al. 1994[31]	Lincoln et al. 2004[32]	Markle-Reid et al. 2011[33]	Mayo et al. 2008[34]	Mulders et al. 1989[35]	Roderick et al. 2001[36]	Ryan et al. 2006[37]	Ytterberg et al. 2000[38]	Total category (%)
Additional statistics	Yes	No	Yes	No	Yes	No	No	No	Yes	Yes	No	No	No	No	
(max. 8)	5	5	5	3	2	3	2	4	7	6	3	4	6	1	**56 (50%)**
Results															
Participation flow	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Losses and exclusion	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Period recruitment and follow-up	No	Yes	No	No	No	No	No	No	No	No	No	No	No	No	
Reason ending trial	Yes	No	No	No	No	No	No	No	No	No	No	No	No	No	
Baseline data	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Numbers analysed	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Outcomes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	
Binary outcomes	NA	No	NA	NA	No	No	No	No	No	No	No	No	No	No	
Ancillary analysis	Yes	Yes	Yes	No	Yes	No	No	No	No	No	No	No	No	No	
Harms	No	No	No	No	No	No	No	No	No	No	No	No	No	No	
(max. 10)	4	7	4	4	5	5	5	5	5	5	5	5	5	4	**68 (49%)**

Table 3: Quality assessment of included studies using the Consort statement 2010 *(continued)*

	Allen et al. 2002[25]	Allen et al. 2009[26]	Bjorkdahl et al. 2006[27]	Burton et al. 2005[28]	Forster et al. 2009[29]	Gladman et al. 1993[30]	Gladman et al. 1994[31]	Lincoln et al. 2004[32]	Markle-Reid et al. 2011[33]	Mayo et al. 2008[34]	Mulders et al. 1989[35]	Roderick et al. 2001[36]	Ryan et al. 2006[37]	Ytterberg et al. 2000[38]	Total category (%)
Discussion															
Limitations	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Generalisability	No	No	Yes	No	No	Yes	No	No	Yes	No	No	Yes	No	No	
Interpretation	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
(max. 3)	1	2	3	1	2	3	2	2	3	2	2	3	2	2	**30 (71%)**
Other information															
Registration	No	No	No	No	No	No	No	No	Yes	No	No	No	No	No	
Protocol	No	No	No	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	
Funding	No	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	
(max. 3)	0	1	0	1	1	2	2	1	3	2	1	2	2	2	**20 (48%)**
Total study (%)	**17 (46%)**	**22 (59%)**	**21 (57%)**	**18 (49%)**	**18 (49%)**	**22 (59%)**	**20 (54%)**	**21 (57%)**	**27 (73%)**	**23 (62%)**	**17 (46%)**	**22 (59%)**	**23 (62%)**	**13 (35%)**	

"methods-trial"; "methods-randomization"; "results"; "discussion"; and "other informa-tion". In 4 of these categories ("methods-trial", "methods-randomization", "results" and "other information") ≤50% of the items was reported on average.

Discussion

This systematic review, evaluating the effectiveness of multidisciplinary care for stroke patients living in the community after being discharged home, showed that none of the 11 studies that assessed daily activity reported a favourable effect of the intervention on this outcome. In addition, this review showed that none of the included studies assessed the effects of the intervention on social participation. Furthermore, with regard to qual-ity of life, our review showed that of the 8 studies that assessed the effects of the inter-vention on quality of life, only two showed a favourable effect on this outcome domain. These two interventions were an assessment combined with follow-up visits[25] and a rehabilitation intervention[37]. These interventions differed considerably in organization, disciplines involved, duration and intensity, which makes comparison and identification of essential care elements of effective multidisciplinary care impossible.

Previous reviews, which assessed the effects of home-based interventions provided by multidisciplinary teams, physiotherapist or occupational therapists, showed a sta-tistically significant favourable effect of these interventions on daily activities[18,21]. This appears to be in contrast with the findings of the present review. However, our review focused only on multidisciplinary interventions and only reported only significant results. The results of the multidisciplinary studies included in previous reviews are in favour of the treatment on daily activities, but their results are non-significant[18,21], which is in line with our findings. In addition, a previous review, which focused on the effects of therapy based interventions 1 year or more after stroke, found inconclusive evidence for the effectiveness of therapy-based interventions and reported that interventions were different in design, type of intervention and outcome, which is consistent with the findings of this review[19].

The methodological quality of the 14 studies differed considerably and ranged between 35% and 73%, indicating that substantial quality improvements can be made in future research. For example, description of trial design, implementation procedure and period of recruitment could be reported more accurately. Furthermore, the generalization of the results should be reported because it can provide valuable information for clinical use. However, we have to consider that some items (such as blinding, serious harms and interim analysis) are less applicable for studies evaluating non-pharmacological inter-

ventions, which also decrease the percentage of reported items and thus the quality. Furthermore with regard to research in the field of stroke, we consider it very important to report the time between stroke and start of the intervention to facilitate a proper comparison of the effects of the different types of interventions and to gain insight into the phase in which these patients were at time of the intervention (rehabilitation or long-term care).

We conclude there is only limited evidence for the effectiveness of multidisciplinary care programs for community living stroke patients after being discharged home. There may be several explanations for the lack of effectiveness of these interventions. First, it is possible that the time between stroke and the start of the intervention was in general too long, which may make it more difficult to achieve significant favourable effects[39]. This assumption is supported by the fact that two recent studies that evaluated interventions, that started in the acute phase and continued in the home setting (early supported discharge), showed favourable effects on functional outcome, even after 5 years[40,41]. A second explanation might be found in the design of the studies. The experimental intervention was in almost all included studies compared to care as usual which is in general poorly described in the studies. It is therefore unclear whether the contrast between the experimental care and care as usual was big enough to raise a substantial effect. A third explanation might be found in the fact that, for most interventions, it was not described whether the intervention was based on a specific theoretical framework and/or evidence of previous research. Furthermore, most studies did not present a clear description of the intensity and contents of the programme. It is therefore possible that the quality of the interventions was simply too low, because the interventions were insufficiently based on theoretical frameworks and/or evidence from previous research.

A major strength of our review is the inclusion of 8 studies that had not been evaluated by previous reviews. A limitation of this review may be the selection of appropriate search terms for the interventions, because multidisciplinary care can be described by many different terms. Therefore it is possible that we have missed relevant studies. Another limitation may be the fact that we focused in our review on 3 outcome measures: daily activity, quality of life and social participation. Although we have only found two effective interventions regarding quality of life, the included interventions may have had favourable effects on other outcomes such as depression, cost reduction or care satisfaction, which we did not consider in this review.

Our systematic review showed that only 2 of the 8 multidisciplinary interventions that assessed quality of life reported favourable effects on quality of life in stroke patients discharged home after hospitalization or inpatient rehabilitation. Furthermore, none of

the studies showed favourable effects on daily activity. Therefore there is still a great need for additional high-quality studies assessing the effectiveness of different types of multidisciplinary care for stroke patients after being discharged home. It seems important that future intervention programmes are based on theoretical frameworks and/or results of previous research, in order to increase the (potential) quality of the programmes. In addition, future research into the effects of multidisciplinary care among stroke patients discharged home should also evaluate the effects on social participation, as this important outcome has not been included in previous research.

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References

1. Weimar C, Kurth T, Kraywinkel K, Wagner M, Busse O, Haberl RL, Diener HC. Assessment of functioning and disability after ischemic stroke. Stroke 2002;33:2053-59.
2. Mackay J, Mensah G. Atlas of heart disease and stroke. World Health Organization Geneva 2004.
3. Tilling K, Sterne JA, Rudd AG, Glass TA, Wityk RJ, Wolfe CD. A new method for predicting recovery after stroke. Stroke 2001;32:2867-73.
4. Lincoln NB, Gladman JR, Berman P, Noad RF, Challen K. Functional recovery of community stroke patients. Disability rehabilitation 2000;22:135-39.
5. Wade DT, Collen FM, Robb GF, Warlow CP. Physiotherapy intervention late after stroke and mobility. Bmj 1992;304:609-13.
6. Patel MD, Tilling K, Lawrence E, Rudd AG, Wolfe CD, McKevitt C. Relationship between long-term stroke disability, handicap and health-related quality of life. Age Ageing 2006;35:273-79.
7. Cramer SC. Changes in motor system function and recovery after stroke. Restor Neurol Neurosci 2004;22:231-38.
8. D'Alisa S, Baudi S, Mauro A, Miscio G. How does stroke restrict participation in long-term post-stroke survivors? Acta Neurol Scand 2005;112:157-62.
9. Clarke PJ, Black SE, Badley EM, Lawrence JM, Williams JI. Handicap in stroke survivors. Disabil Rehabil 1999;21:116-23.
10. Lightbody CE, Baldwin R, Connolly M, Gibbon B, Jawaid N, Leathley M, Sutton C, Watkins CL. Can nurses help identify patients with depression following stroke? A pilot study using two methods of detection. J Adv Nurs 2007;57:505-12.
11. Morrison V, Pollard B, Johnston M, MacWalter R. Anxiety and depression 3 years following stroke: demographic, clinical, and psychological predictors. J Psychosom Res 2005;59:209-13.
12. Rasquin SM, Lodder J, Ponds RW, Winkens I, Jolles J, Verhey FR. Cognitive functioning after stroke: A one-year follow-up study. Dement Geriatr Cogn Disord 2004;18:138-44.

13. Desrosiers J, Noreau L, Rochette A, Bravo G, Boutin C. Predictors of handicap situations following post-stroke rehabilitation. Disabil Rehab 2002;24:774-85.
14. Dijkerman HC, Wood VA, Hewer RL. Long-term outcome after discharge from a stroke rehabilitation unit. J R Coll Physician Lond 1996;30:538-46.
15. Murray J, Ashworth R, Forster A, Young J. Developing a primary care-based stroke service: A review of the qualitative literature. Br J Gen Pract 2003;53:137-42.
16. Stroke Unit Trialists' Collaboration. Organised inpatient (stroke unit) care for stroke. Cochrane Database Syst Rev 2002:CD000197.
17. Langhorne P. Developing comprehensive stroke services: An evidence-based approach. Postgrad Med J 1995:71:733-7.
18. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database Syst Rev 2003;1:DOI: 10.1002/14651858.CD002925.
19. Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF. Therapy-based rehabilitation services for patients living at home more than one year after stroke. Cochrane Database Syst Rev 2008:CD005952.
20. Boter H, de Haan RJ, Rinkel GJ. Regional differences in the use of out patient services by stroke patients after hospitalisation. Eur Neurol 2005;53:10-4.
21. Legg L, Langhorne P. Rehabilitation therapy services for stroke patients living at home: Systematic review of randomised trials. Lancet 2004;363:352-6.
22. Legg LA, Drummond AE, Langhorne P. Occupational therapy for patients with problems in activities of daily living after stroke. Cochrane Database Syst rev 2006:CD003585.
23. Hillier S, Inglis-Jassiem G. Rehabilitation for community-dwelling people with stroke: Home or centre based? A systematic review. Int J Stroke 2010;5:178-86.
24. Schulz KF, Altman DG, Moher D. CONSORT 2010 Statement: Updated guidelines for reporting parallel group randomized trials. Annals of Internal Medicine 2010;152(1):1-7.
25. Allen KR, Hazelett S, Jarjoura D, Wickstrom GC, Hua K, Weinhardt J, Wright K. Effectiveness of a post-discharge care management model for stroke and transient ischemic attack. A randomised trial. J Stroke Cerebrovasc Dis 2002;11:88-98.
26. Allen K, Hazelett S, Jarjoura D, Hua K, Wright K, Weinhardt J, Kropp D. A randomised trial testing the superiority of a postdischarge care management model for stroke survivors. J Stroke Cerebrovasc Dis 2009;18:443-52.
27. Bjorkdahl A, Nilsson AL, Grimby G, Sunnerhagen KS. Does a short period of rehabilitation in the home setting facilitate functioning after stroke? A randomised controlled trial. Clin Rehab 2006;20:1038-49.
28. Burton C, Gibbon B. Expanding the role of the stroke nurse: A pragmatic clinical trial. J Adv Nurs 2005;52:640-50.
29. Forster A, Young J, Green J, Patterson C, Wanklyn P, Smith J, Murray J, Wild H, Bogle S, Lowson K. Structured re-assessment system at 6 months after a disabling stroke: A randomised controlled trial with resource use and cost study. Age Ageing 2009;38:576-83.
30. Gladman JR, Lincoln NB, Barer DH. A randomised controlled trial of domiciliary and hospital-based rehabilitation for stroke patients after discharge from hospital. J Neurol Neurosurg Psychiatry 1993;56:960-6.
31. Gladman JR, Lincoln NB. Follow-up of a controlled trial of domiciliary stroke rehabilitation (domino study). Age Ageing 1994;23:9-13.
32. Lincoln N, Walker M, Dixon A, Knights P. Evaluation of a multiprofessional community stroke team: A randomized controlled trial. Clinical Rehabilitation 2004;18:40-7.

33. Markle-Reid M, Orridge C, Weir R, Browne G, Gafni A, Lewis M, Walsh M, Levy C, Daub S, Brien H, Roberts J, Thabane L. Interprofessional stroke rehabilitation for stroke survivors using home care. Can J Neurol Sci. 2011 Mar;38(2):317-34.

34. Mayo NE, Nadeau L, Ahmed S, White C, Grad R, Huang A, Yaffe MJ, Wood-Dauphinee S. Bridging the gap: The effectiveness of teaming a stroke coordinator with patient's personal physician on the outcome of stroke. Age Ageing 2008;37:32-8.

35. Mulders A, De Witte L, Diederiks J. Evaluation of a rehabilitation after-care programme for stroke patients. Journal of Rehabilitation Sciences 1989;2:97-103.

36. Roderick P, Low J, Day R, Peasgood T, Mullee MA, Turnbull JC, Villar T, Raftery J. Stroke rehabilitation after hospital discharge: A randomized trial comparing domiciliary and day-hospital care. Age Ageing 2001;30:303-10.

37. Ryan T, Enderby P, Rigby AS. A randomised controlled trial to evaluate intensity of community-based rehabilitation provision following stroke or hip facture in old age. Clin Rehab 2006;20:123-31.

38. Ytterberg C, Anderson Malm S, Britton M. How do stroke patients fare when discharged straight to their homes? A controlled study on the significance of hospital follow-up after one month. Scand J Rehabil Med 2000;32:93-6.

39. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. The Lancet 2011;377:1693-702.

40. Thorsén AM, Holmqvist LW, de Pedro-Cuesta J, von Koch L. A randomized controlled trial of early supported discharge and continues rehabilitation at home after stroke: five-year follow-up of patient outcome. Stroke 2005;36:297-302.

41. Fjaertoft H, Rohweder G, Indredavik B. Stroke unit care combined with early supported discharge improves 5-year outcome: a randomized controlled trial. Stroke 2011;42:1707-11.

2

CHAPTER 3

Factors associated with successful home discharge after inpatient rehabilitation in frail older stroke patients

Background

Stroke is a highly prevalent disease among older people and can have a major impact on daily functioning and quality of life. When community-dwelling older people are hospitalized due to stroke, discharge to an intermediate care facility for geriatric rehabilitation is indicated when return to the previous living situation is expected but not yet possible. However, a substantial proportion is still unable to return home after discharge and has to be admitted to a residential care setting. This study aims to identify which factors are associated with home discharge after inpatient rehabilitation among frail and multimorbid older stroke patients.

Methods

This study is a longitudinal cohort study among 92 community-dwelling stroke patients aged 65 years or over. All patients were admitted to one of eight participating intermediate care facilities for geriatric rehabilitation, under the expectation to return home after rehabilitation. We examined whether 16 potentially relevant factors (age; sex; household situation before admission; stroke history; cardiovascular disorders; diabetes mellitus; multimorbidity; cognitive disability; neglect; apraxia; dysphagia; urinary and bowel incontinence; emotional problems; sitting balance; daily activity level; and independence in activities of daily living) measured at admission were associated with discharge to the former living situation. Logistic regression analysis was used for statistical analysis.

Results

Mean age of the patients was 79.0 years (SD 6.4) and 51.1% was female. A total of 71 patients (77.1%) were discharged to the former living situation within six months after the start of geriatric rehabilitation. Of the 16 factors analysed, only a higher level of independence in activities of daily living at admission was significantly associated with home discharge.

Conclusions

Our study shows that the vast majority of previously identified factors predicting home discharge among stroke patients, could not predict home discharge among a group of frail and multimorbid older persons admitted to geriatric rehabilitation. Only a higher level of independence in activities of daily living at admission was significantly related to home discharge. Additional insight in other factors that might predict home discharge after geriatric rehabilitation among this specific group of frail older stroke patients, is needed. Trial registration: ISRCTN ISRCTN62286281. Registered 19-3-2010.

Keyword: Stroke, Rehabilitation, Older people, Prediction, Discharge destination, Community

Abstract

Background

Stroke is a highly prevalent disease among older people and can have a major impact on daily functioning and quality of life. The prevalence of stroke among Dutch people of 65 years or older is estimated at 54 per 1,000 males and 40 per 1,000 females[1]. In the Netherlands, after admission to a hospital, about one third of older stroke patients is referred to an intermediate care facility for (geriatric) rehabilitation, which is specifically aimed at the rehabilitation of frail and multimorbid community-dwelling older people[2].

In the Netherlands, admission to an intermediate care facility for geriatric rehabilitation is indicated for community-dwelling frail older people, who are expected to have the capacity to improve to a functional level that enables discharge to their former living situation within a maximum of six months of rehabilitation[2]. However, adequately predicting functional recovery and home discharge for this group of older people is a challenge for care professionals, due to the multimorbidity and frailty of these patients. As a result, ultimately up to 25% of these older stroke patients appears not to be able to return to their previous living situation after geriatric rehabilitation[3]. Often, these patients are admitted to a nursing home or other residential care setting[4,5]. More insight into factors associated with home discharge of frail and multimorbid older stroke patients after geriatric rehabilitation is needed to support care professionals to make an adequate prognosis of discharge destination and to support them to focus their treatment on increasing the chances of home discharge.

Although various studies have assessed predictors of discharge destination of stroke patients, the number of studies conducted exclusively in frail and multimorbid stroke patients in geriatric rehabilitation is limited compared to the much larger body of literature performed among the general population of stroke patients.

However, studies among such frail and multimorbid older patients admitted to intermediate care facilities for rehabilitation, show that the following factors are negatively associated with home discharge; high age[5,6], female sex[7], living alone[7-10], absence of social support[7,9-11], hemorrhagic stroke[7], loss of conciousness[8], cognitive disability[6-10,12], neglect[5,7,8], unawareness of illness[8], severe paralysis[8], spasticity[8], urinary and bowel incontinence[6,8,10,12], limited postural control[5], hemianopsia[8], and dependence in activities of daily living[6-11]. Furthermore, in order to prevent missing potential relevant predictors of home discharge, we also performed a quick scan of studies performed among the general population of stroke patients for additional factors related to home discharge after stroke rehabilitation[13-22].

Based on these two groups of studies, five categories of factors measured at admission to rehabilitation are found to be negatively correlated to home discharge after rehabilitation of stroke patients:

1) *Demographic characteristics:* high age[5,6,13,14,16,17,19,20,22], non-white race[13], female sex[7,13,14,17].

2) *Social and environmental characteristics:* living alone (i.e. not sharing a household)[7-10,13-15,17,18,21], absence of social support[7,9-11,18,19], insufficient professional care[19], high need for home adaptations[19], and limited private financial means[19].

3) *Stroke related health status:* stroke history[13,17], hemorrhagic stroke[7,13,17], more severe stroke[2,16,19,22], larger stroke volume[13,14,16], loss of consciousness[8,13,16,17,19], cognitive disability[6-10,12-17,19], neglect[5,7,8,14,16,17,19], apraxia[16,17,19], unawareness of illness[8,14,17], severe paralysis[8,14,16,17,19], impairment in movement[17,19,20] spasticity[8], disorientation in time and place[16,17,19], emotional problems[13,19], dysphagia[15,16], urinary and bowel incontinence[6,8,10,12,13,15-17,19], limited postural control[5], restrictions in sitting balance[16,19], and hemianopsia[8,16,17].

4) *General health status:* high blood pressure[13,16], diabetes mellitus[13], pneumonia[13], cardiovascular disorders[13,16], multimorbidity[13,16], personality disorder[19].

5) *Functional status:* communication disability[19], low daily activity level[13], dependence in activities of daily living [6-13,16,17,19-21].

The factors that were found to be related to home discharge in at least five of our selected studies were dependence in activities of daily living (n=13 studies), cognitive disability (n=12), living alone (n=10), high age (n=9), urinary and bowel incontinence (n=9), neglect (n=7), absence of social support (n=6), loss of consciousness (n=5), and severe paralysis (n=5). Due to the large number of (potential) predictors of home discharge reported in literature, it is important for care professionals in intermediate care facilities for geriatric rehabilitation to gain insight in which factors most strongly correlate with home discharge among frail and multimorbid older stroke patients.

Therefore, the aim of this study is to identify which factors are associated with home discharge after inpatient rehabilitation among frail and multimorbid older stroke patients. For this purpose, in our study we have combined a set of factors previously found to be related to home discharge, in order to gain insight in the factors most strongly correlating with home discharge of frail and multimorbid stroke patients after inpatient geriatric rehabilitation.

Methods

Design

We performed a longitudinal cohort study, based on data from the MAESTRO-study[23] which is a two group multicenter randomized controlled trial evaluating the effects of a new geriatric rehabilitation program for older people with stroke admitted to an intermediate care facilities for geriatric rehabilitation. For this secondary analysis we used data of the patients allocated to the control group, who received usual care based on the Dutch guidelines for stroke rehabilitation[24]. Patients from the experimental group were excluded because of the possible intervention effect.

Study sample

The sample for this study consisted of 92 persons admitted to an intermediate care facility for geriatric rehabilitation in the period November 2010 to December 2014. Inclusion criteria for these patients were: (1) age 65 year or older, (2) living independently in the community before stroke, and (3) being admitted to one of eight intermediate care facilities for geriatric rehabilitation in the south of the Netherlands under the prognosis that they would be able to return to their previous living situation after rehabilitation (as assessed two weeks after admission by clinical judgement of a multidisciplinary team at the intermediate care facility for geriatric rehabilitation). Patients, who were medically unstable or had severe cognitive disabilities and were unable to start rehabilitation, were excluded[23]. Informed consent was obtained from all participants. The study protocol has been approved by the medical ethics committee of Maastricht University Medical Centre (MUMC+), the Netherlands (ISRCTN62286281, NTR2412). The study protocol has been published elsewhere[23].

Data collection

Data were gathered by means of registration forms administered by care professionals of the intermediate care facility for geriatric rehabilitation and structured interviews with patients[23]. The interviews with the patients were conducted by trained research assistants at the start of the rehabilitation treatment.

Factors measured at admission to the intermediate care facility for geriatric rehabilitation

All potential predictors of home discharge of stroke patients after rehabilitation (described above) that were also measured in the MAESTRO study were selected for the present study. The final set of potentially predictive factors was divided in the five categories mentioned before: demographic characteristics, social and environmental factors, stroke related health status, general health status and functional status as pre-

sented below. The following 16 factors assessed at admission to the intermediate car facility for geriatric rehabilitation were available in the MAESTRO-dataset:

1) *Demographic characteristics*: age, sex;
2) *Social characteristics*: household situation before admission (living alone or with others);
3) *Stroke related health status*: stroke history, cognitive disability, neglect, apraxia, dysphagia, urinary and bowel incontinence, and sitting balance;
4) *General health status*: emotional problems, cardiovascular disorders, diabetes mellitus, multimorbidity;
5) *Functional status*: daily activity level, independence in activities of daily living.

Stroke history, neglect, apraxia, urinary and bowel incontinence, sitting balance, cardiovascular disorders and diabetes mellitus, were retrieved from patient records and dichotomized (present or not present). Information regarding household situation before admission (i.e. living alone or sharing a household with one or more persons) was assessed by means of the interview with the patient at admission to geriatric rehabilitation. In the same interview, also the factors emotional problems, multimorbidity, daily activity level, independence in activities of daily living and cognitive disability were assessed. Emotional problems were measured by the emotional problems domain of the EuroQol-5D (EQ-5D)[25]. This item was dichotomized in (0) no emotional problems, and (1) emotional problems. Multimorbidity was measured by a variable which included 17 different medical conditions which are scored as present (1) or not present (0)[26]. The summed multimorbidity score can range from 0-17 with higher scores indicating more conditions present. Daily activity level was measured by the Frenchay Activity Index (FAI)[27]. The FAI measures the daily activity level of stroke patients and consists of 15 items (range 15-60 with higher scores indicating better functioning). The level of independence in activities of daily living was assessed with the Katz Index of Independence in Activities of Daily Living scale (Katz-15)[28] consisting of 15 items (range 0-15 with lower scores indicating a higher level of independence). Cognitive status was measured by the 11-item Minimal Mental State Examination (MMSE; range 0-30 with higher scores indicating better functioning)[29].

Discharge destination

Data regarding the living situation six months after admission (moment of discharge) to geriatric rehabilitation were gathered from the discharge registration of the eight participating rehabilitation units. The available data were dichotomized into (1) discharged to the previous living situation (i.e. home discharge) and (0) not discharged to the previous living situation (i.e. still in geriatric rehabilitation or admitted to nursing home, care home or service apartment).

Statistical analysis

First, descriptive statistics were used to calculate means or proportions of the potential prognostic factors. Second, a Pearson R correlation analysis was applied to assess strength of the univariate relationship between the potential prognostic factors, and discharge destination. For some categorical factors (i.e. gender, household situation, apraxia, neglect, dysphagia) a chi-square test was applied. Pearson correlation is a measure of strength, whereas Ch-square is a test statistics. All categorical variables are dichotomous. Thus a Pearson correlation can be calculated (instead of phi coefficient; they are exactly the same). Third, a two-level logistic regression analysis was conducted to study the relationship between the potential prognostic factors and discharge destination. The first level consists of the patients and the second level consists of the organizations, because the patients are nested within the organizations. In each step of the analysis the factor with the highest p-value was eliminated until only factors remained with a p-value below 0.10. The association of each individual variable was expressed in an odds ratio, 95% confidence interval, and p-value. All statistical analyses were conducted using SPSS software version 25 for Windows.

Results

Patient characteristics measured at baseline are presented in table 1. The mean age of the patients was 79.0 (SD 6.4) year with a range of 65 to 94 years. About half of the patients (n=47, 51.1%) were female and 43 patients (47.3%) lived alone before admission. On average, the patients had four different medical conditions. After six months 71 patients (77.1%) had returned to their former living situation, and 21 (22.8%) patients were admitted to sheltered housing or nursing home see table 2).

Table 3 presents the bivariate correlations between the 16 included prognostic factors and discharge destination. The analysis shows that only one of the 16 potential prognostic factors, independence in activities of daily living, is significantly related to home discharge (r=-0.38, p=0.00). The logistic regression analysis presented in table 4 also shows that only a higher level of independence in activities of daily living is significantly related to home discharge (OR=0.70, p=0.01).

Table 1: Patient characteristics measured at baseline (n=92)

Demographic characteristics	Scores
Mean age (SD)	79.0 (6.4)
Female gender N (%)	47 (51.1)
Social characteristics	
Household situation: living alone N (%)	43 (47.3)
Stroke related health status	
Stroke history N (%)	28 (29.2)
Cognitive disability (MMSE) Mean (range)	22 (0-<u>30</u>)*
Neglect N (%)	21 (21.9)
Apraxia N (%)	23 (24.0)
Dysphagia N (%)	28 (30.8)
Urinary and bowel incontinence N (%)	34 (37.0)
Restrictions in sitting balance N (%)	73 (76.0)
General health status	
Emotional problems N (%)	38 (41.3)
Cardiovascular disorders N (%)	22 (23.9)
Diabetes mellitus N (%)	25 (27.2)
Multimorbidity Mean (SD)	4 (1.67)
Functional status	
Daily activity level (FAI) Mean (range)	38 (15-4<u>5</u>)*
Independence in activities of daily living (Katz-15) Mean (range)	6 (<u>0</u>-15)*

* the underlined score is the most favorable score.

Table 2: Discharge destination of the patients after 6 months

Discharge destination	n=92
Discharged to former living situation N (%)	71 (77.1)
Discharged to other setting N (%)	21 (22.8)
• Sheltered housing N (%)	1 (1.1)
• Care home (%)	13 (14.1)
• Nursing home N (%)	7 (7.6)

Discussion

In the Netherlands, specialized intermediate care facilities for geriatric rehabilitation aim to enable community-living frail older stroke patients to return to their previous living situation after rehabilitation. However, due to the complex nature of stroke, and the frailty level of these older multimorbid stroke patients (as indicated by the average number of four medical conditions), predicting functional recovery and discharge destination are considered very challenging.

Table 3: Bivariate Correlation analyses of predictive factors and discharge to former living situation

Predictive factor	Pearson r	P
Demographic characteristics		
Age	-0.04	0.69
Gender	-0.09	0.37
Social characteristics		
Household situation: living alone	0.14	0.20
Stroke related health status		
Stroke history	0.12	0.26
Cognitive disability (MMSE)	0.09	0.38
Neglect	-0.03	0.80
Apraxia	-0.06	0.56
Dysphagia	-0.13	0.23
Urinary and bowel incontinence	0.08	0.47
Restrictions in sitting balance	0.12	0.25
General health status		
Emotional problems	-0.15	0.16
Cardiovascular disorders	-0.01	0.90
Diabetes mellitus	0.09	0.42
Multimorbidity	-0.10	0.35
Functional status		
Daily activity level (FAI)	0.01	0.96
Independence in activities of daily living (Katz-15)	-0.38	0.00*

*=significant at 0.05 level

In the present study, we examined 16 factors that, based on the literature, might be potentially associated with discharge destination of older stroke patients admitted to geriatric rehabilitation. These potential prognostic factors were: age; sex; household situation before admission; stroke history; cognitive disability; neglect; apraxia; dysphagia; urinary and bowel incontinence; emotional problems; cardiovascular disorders; diabetes mellitus; multimorbidity; sitting balance; daily activity level; and independence in activities of daily living. A two-level multivariable logistic regression analysis revealed that only a higher level of independence in activities of daily living at admission (as measured with Katz-15) was significantly associated with being discharged to the former living situation within six months after admission to geriatric rehabilitation. The fifteen other factors were not significantly associated with home discharge.

Our results regarding the relationship between level of independence in activities of daily living at admission and discharge destination after rehabilitation are in accordance with results of previous studies in the general population of stroke patients [13,16,17,19-21]

Table 4: Logistic regression analyses of associated home discharge predictors

Predictive factors	OR	P	95% CI for OR
Demographic Characteristics			
Age	0.97	0.68	0.84 – 1.12
Gender	1.93	0.48	0.31 – 11.89
Social characteristics			
Household situation: living alone	1.95	0.42	0.37 – 10.26
Stroke related health status			
Stroke history	2.72	0.26	0.46 – 15.95
Cognitive disability (MMSE)	0.99	0.88	0.83 – 1.17
Neglect	0.66	0.62	0.13 – 3.47
Apraxia	1.01	1.00	0.15 – 6.58
Dysphagia	1.33	0.73	0.27 – 6.61
Urinary and bowel incontinence	1.25	0.79	0.23 – 6.68
Restrictions in sitting balance	1.14	0.87	0.22 – 6.05
General health status			
Emotional problems	0.48	0.34	0.11 – 2.17
Cardiovascular disorders	0.93	0.94	0.17 – 5.24
Diabetes mellitus	3.86	0.18	0.53 – 28.28
Multimorbidity	0.83	0.46	0.49 – 1.39
Functional status			
Daily activity level (FAI)	1.02	0.78	0.90 – 1.15
Independence in activities of daily living (Katz-15)	0.70	0.01*	0.53 – 0.93

*significant at 0.05 level, ICC of the two-level model is 0.32

and among older stroke patients[6-12], which showed that independence in activities of daily living was the most frequently mentioned predictor in the studies included in our literature search.

However, for the other fifteen prognostic factors, no significant association with discharge destination in our sample of frail and multimorbid older stroke patients could be identified. This is rather unexpected, because a significant relationship of these prognostic factors with discharge destination was observed in one or more previous studies among the general and/or older population of stroke patients. [5-10,12-22]. The fact that our findings are inconsistent with current literature can be explained by several factors. First, we also included prognostic factors in our analysis that were only reported in studies among the general population of stroke patients (i.e. apraxia, dysphagia, sitting balance, emotional problems, cardiovascular disease, diabetes mellitus, and daily activity level). It is likely that our sample of geriatric rehabilitation patients is considerably more complex compared to the general population of stroke patients because geriatric rehabilitation

patients are often frail, multimorbid and may also have a weaker social network, so there might be other prognostic factors present which can potentially influence the chances of home discharge. However, the majority of prognostic factors included in our analyses were (also) reported by studies among the population of older stroke patients who received rehabilitation in an intermediate care facility. A second possible explanation is that there are considerable differences between our study sample and the samples of the majority of these other studies. Our study sample consisted of frail and multimorbid stroke patients, and it is unclear whether studies performed in other countries included a comparable frail and multimorbid population. In addition, in the Netherlands people with severe cognitive impairments (such as dementia) are in general not admitted to geriatric rehabilitation due to a lack of trainability. It is possible that in countries where persons with severe cognitive impairments can be admitted to geriatric rehabilitation, cognitive impairment might be a statistically significant predictor of home discharge.

A third explanation might be the fact that some of the prognostic factors included in our study, are measured in a different way compared to previous studies. Instruments can differ for example with regard to their sensitivity or with regard to the specific aspects of the same phenomenon they assess, which might have resulted in different correlations

This study has several limitations. First, several prognostic factors were measured in a dichotomous way, such as sitting balance, apraxia and neglect, which may have resulted in some loss of information. It is possible that a more comprehensive way of assessing these factors would have led to other results in our analysis. Second, this study is a secondary analysis of existing data. For this reason, we were not able to include all potential relevant predictors of home discharge in our study found in previous studies among older patients admitted to intermediate care facilities for rehabilitation, including social support[7,9-11], hemorrhagic stroke [7], loss of consciousness[8], unawareness of illness[8], severe paralysis[8], spasticity[8], postural control[5], and hemianopsia[6-11]. Most of these factors were only found in one single or a few studies, however social support was found in six other studies, and loss of consciousness and severe paralysis in five studies, so it remains unclear whether these factors might also be relevant predictors in our frail population. Although household situation (i.e. living alone versus living with others) might be considered an indicator of social support it seems likely that this variable does not differentiate enough within our frail population.

Almost half (47%) of our population lives alone, and probably a considerable number of the other half has a partner who is also frail and needs support. Therefore, in a frail and multimorbid population, it might be better to assess the availability of informal caregivers, and social support in a more comprehensive way. Therefore, it is possible

that we missed some relevant prognostic factors especially in the domain of social support. Furthermore, researchers in the domain of stroke rehabilitation in frail older people might have collectively missed or understudied potential relevant prognostic factors for home discharge, such as the level of frailty, (post stroke) depression, availability of family caregivers and/or professional caregivers, motivation and preferences of patients and family caregivers, and financial means. A third limitation is the size of our sample. Although bivariate analyses revealed that only a higher level of independence in activities of daily living at admission was significantly related to home discharge, for the logistic regression analyses our sample size can be considered relatively small in relation to the relatively large number of prognostic factors in our logistic regression. However, bivariate analysis also revealed no significant correlations between the other prognostic factors and discharge destination. A fourth limitation is the fact that our study is performed in only one country (the Netherlands). It is possible that due to cultural differences and/or differences in healthcare systems, in other countries different factors might be relevant for home discharge after stroke rehabilitation among frail older persons.

Conclusion

In conclusion, our study shows that the vast majority of prognostic factors reported in literature to be related to home discharge among stroke patients after rehabilitation, were not correlated to home discharge within our study sample of frail and multimorbid older persons admitted to geriatric rehabilitation. Our analyses showed that only a higher level of independence in activities of daily living at admission to geriatric rehabilitation is associated with discharge to the former living situation, six months after starting stroke rehabilitation. It is important to gain additional insight in possible other factors that might predict home discharge among frail older stroke patients after geriatric rehabilitation, such as the level of frailty, factors related to social support, the availability of family and/or caregivers, and motivational factors.

Declarations

Ethics approval and consent to participate
Ethical apporoval was provided by the medical ethics committee of Maastricht University Medical Centre (MUMC+), the Netherlands (ISRCTN62286281, NTR2412). All participants gave written informed consent to take part in the study.

Consent to publish
Not applicable.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests
The authors declare that they have no competing interests.

Authors' Contributions
TV, JvH, FT, GK, JS and JV were involved in the design of the study, data collection, and data analysis. TV wrote drafts of the manuscript. JvH supervised data analysis. JvH, FT, GK, JS and JV were involved in the interpretation of the results. JvH, JV, and JS supervised the project. All authors read, critically reviewed and approved the final manuscript.

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References

1. Vaartjes I, Bots ML, Poos MJJC. Hoe vaak komt een beroerte voor en hoeveel mensen sterven eraan? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM, 2014.
2. Behandelkaders Geriatrische Revalidatie, Verenso 2010.
3. The Influence of Activity-Based Funding on Treatment Intensity and Length of Stay of Geriatric Rehabilitation Patients. Bouwstra H, Wattel LM, de Groot AJ, Smalbrugge M, Hertogh CM. J Am Med Dir Assoc. 2017 Jun 1;18(6):549.e15-549.e22.
4. Buijck BI, Zuidema SU, Spruit-van Eijk M, Geurts AC, Koopmans RT. Neuropsychiatric symptoms in geriatric patients admitted to skilled nursing facilities in nursing homes for rehabilitation after stroke: a longitudinal multicenter study. Int J Geriatr Psychiatry. 2012 Jul;27(7):734-41.
5. Spruit-van Eijk M, Zuidema SU, Buijck BI, Koopmans RT, Geurts AC. Determinants of rehabilitation outcome in geriatric patients admitted to skilled nursing facilities after stroke: a Dutch multi-centre cohort study. Age Ageing. 2012 Nov;41(6):746-52.
6. Thommessen B, Bautz-Holter E, Laake K. Predictors of outcome of rehabilitation of elderly stroke patients in a geriatric ward. Clin Rehabil. 1999 Apr;13(2):123-8.
7. Mutai H, Furukawa T, Araki K, Misawa K, Hanihara T. Factors associated with functional recovery and home discharge in stroke patients admitted to a convalescent rehabilitation ward. Geriatr Gerontol Int. 2012 Apr;12(2):215-22.
8. Kalra L, Smith DH, Crome P. Stroke in patients aged over 75 years: outcome and predictors. Postgrad Med J. 1993 Jan;69(807):33-6.
9. Denti L, Agosti M, Franceschini M.Outcome predictors of rehabilitation for first stroke in the elderly. Eur J Phys Rehabil Med. 2008 Mar;44(1):3-11.
10. Gialanella B, Santoro R, Ferlucci C. Predicting outcome after stroke: the role of basic activities of daily living predicting outcome after stroke. Eur J Phys Rehabil Med. 2013 Oct;49(5):629-37.
11. Lindenberg K, Nitz JC, Rahmann A, Bew P. Predictors of discharge destination in a geriatric population after undergoing rehabilitation. J Geriatr Phys Ther. 2014 Apr-Jun;37(2):92-8.
12. Ergeletzis D, Kevorkian CG, Rintala D. Rehabilitation of the older stroke patient: functional outcome and comparison with younger patients. Am J Phys Med Rehabil. 2002 Dec;81(12):881-9.
13. Almenkerk Sv, Smalbrugge M, Depla MF, Eefsting JA, Hertogh CM. What predicts a poor outcome in older stroke survivors? A systematic review of the literature. Disabil Rehabil. 2013 Oct;35(21): 1774-82.
14. Jehkonen M, Ahonen JP, Dastidar P, Koivisto AM, Laippala P, Vilkki J, Molnár G. Predictors of discharge to home during the first year after right hemisphere stroke. Acta Neurol Scand. 2001 Sep;104(3): 136-41.
15. Massucci M, Perdon L, Agosti M, Celani MG, Righetti E, Recupero E, Todeschini E, Franceschini M; Italian Cooperative Research (ICR2). Prognostic factors of activity limitation and discharge destination after stroke rehabilitation. Am J Phys Med Rehabil. 2006 Dec;85(12):963-70.
16. Meijer R, Ihnenfeldt DS, de Groot IJ, van Limbeek J, Vermeulen M, de Haan RJ. Prognostic factors for ambulation and activities of daily living in the subacute phase after stroke. A systematic review of the literature. Clin Rehabil. 2003 Mar;17(2):119-29.
17. Meijer R, Ihnenfeldt DS, van Limbeek J, Vermeulen M, de Haan RJ. Prognostic factors in the subacute phase after stroke for the future residence after six months to one year. A systematic review of the literature. Clin Rehabil. 2003 Aug;17(5):512-20.

18. Meijer R, van Limbeek J, Kriek B, Ihnenfeldt D, Vermeulen M, de Haan R. Prognostic social factors in the subacute phase after a stroke for the discharge destination from the hospital stroke-unit. A systematic review of the literature. Disabil Rehabil. 2004 Feb 18;26(4):191-7.

19. Meijer R, van Limbeek J, Peusens G, Rulkens M, Dankoor K, Vermeulen M, de Haan RJ. The Stroke Unit Discharge Guideline, a prognostic framework for the discharge outcome from the hospital stroke unit. A prospective cohort study. Clin Rehabil. 2005 Oct;19(7):770-8

20. Sánchez-Blanco I, Ochoa-Sangrador C, López-Munaín L, Izquierdo-Sánchez M, Fermoso-Garcia J. Predictive model of functional independence in stroke patients admitted to a rehabilitation programme. Clin Rehabil. 1999 Dec;13(6):464-75.

21. Wilson DB, Houle DM, Keith RA. Stroke rehabilitation: a model predicting return home.West Med. 1991 May;154(5):587-90.

22. Burton JK, Ferguson EEC, Barugh AJ, Walesby KE, MacLullich AMJ, Shenkin SD, Quinn TJ. Predicting Discharge to Institutional Long-Term Care After Stroke: A Systematic Review and Meta analysis. J Am Geriatr Soc. 2018 Jan;66(1):161-169.

23. Vluggen TP, van Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012 Dec 31;12:164.

24. Richtlijn 'Diagnostiek, behandeling en zorg voor patiënten met een beroerte'. Kwaliteitsinstituut voor de gezondheidszorg CBO 2008.

25. Krabbe PF, Stouthard ME, Essink-Bot ML, Bonsel GJ. The effect of adding a cognitive dimension to the EuroQol multiattribute health-status classification system. J Clin Epidemiol. 1999 Apr;52(4):293-301.

26. Lutomski JE, Baars MAE, Schalk BWM, Boter H, Buurman BM, den Elzen WPJ, et al. (2013) The Development of the Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS): A Large-Scale Data Sharing Initiative. PLoS ONE 8(12): e81673.

27. Schuling J, de Haan R, Limburg M, Groenier KH. The Frenchay Activities Index. Assessment of functional status in stroke patients. Stroke. 1993 Aug;24(8):1173-7.

28. Weinberger M, Samsa GP, Schmader K, Greenberg SM, Carr DB, Wildman DS. Comparing proxy and patients' perceptions of patients' functional status: results from an outpatient geriatric clinic. J Am Geriatr Soc. 1992 Jun;40(6):585-8.

29. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975 Nov;12(3):189-98.

3

CHAPTER 4

Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial

Background

Stroke is one of the major causes of loss of independence, decreased quality of life and mortality among elderly people. About half of the elderly stroke patients discharged after rehabilitation in a nursing home still experience serious impairments in daily functioning one year post stroke, which can lead to difficulties in picking up and managing their social life. The aim of this study is to evaluate the effectiveness and feasibility of a new multidisciplinary transmural rehabilitation programme for older stroke patients.

Methods

A two group multicentre randomised controlled trial is used to evaluate the effects of the rehabilitation programme. The programme consists of three care modules: 1) neurorehabilitation treatment for elderly stroke patients; 2) empowerment training for patient and informal caregiver; and 3) stroke education for patient and informal caregiver. The total programme has a duration of between two and six months, depending on the individual problems of the patient and informal caregiver. The control group receives usual care in the nursing home and after discharge.

Patients aged 65 years and over are eligible for study participation when they are admitted to a geriatric rehabilitation unit in a nursing home due to a recent stroke and are expected to be able to return to their original home environment after discharge. Data are gathered by face-to-face interviews, self-administered questionnaires, focus groups and registration forms. Primary outcomes for patients are activity level after stroke, functional dependence, perceived quality of life and social participation. Outcomes for informal caregivers are perceived care burden, objective care burden, quality of life and perceived health. Outcome measures of the process evaluation are implementation fidelity, programme deliverance and the opinion of the stroke professionals, patients and informal caregivers about the programme. Outcome measures of the economic evaluation are the healthcare utilisation and associated costs. Data are collected at baseline, and after six and 12 months. The first results of the study will be expected in 2014.

Trial registration

International Standard Randomised Controlled Trial Register Number IS-RCTN62286281, The Dutch Trial Register NTR2412

Key words: stroke, rehabilitation, aftercare, elderly persons, discharged, nursing home

Abstract

Background

Stroke is one of the major causes of loss of independence, decreased quality of life and mortality among elderly people[1,2]. Each year, about 45,000 people in the Netherlands suffer from stroke and associated functional impairments[3]. Almost 56% of stroke patients are 65 years or older[4].

In contrast to other countries, nursing homes in the Netherlands fulfil an important role in the rehabilitation of older stroke patients[5]. In the Netherlands, 31% of stroke patients are admitted to a geriatric rehabilitation unit in a nursing home after hospital discharge[6-8]. Stroke patients in general are admitted to a geriatric rehabilitation unit in a nursing home when they are over 65 years of age and have coexisting multimorbidity, which means that they are incapable of completing an intensive neurorehabilitation programme in a regular rehabilitation centre.

About half of the stroke patients discharged home after rehabilitation in a nursing home still experience serious impairments in daily functioning one year post stroke, that complicate fulfilling their former social roles[9-12]. Common residual problems of elderly stroke patients are emotional and psychological problems such as depression or cognitive deficits, social problems and health-related problems including rest paralysis and fatigue[13-17]. Besides having negative consequences for the patients, these problems may also increase the care burden and decrease the quality of life of their informal caregivers[18].

Currently, in the Netherlands there is a lack of tailor-made, specialised multidisciplinary aftercare following rehabilitation in nursing homes[19]. This may result in inadequate coping skills with the remaining physical, cognitive and/or psychosocial impairments in their home environment[20,21]. These problems may lead to difficulties in the performance of normal day-to-day activities, fulfilling former social roles, maintaining the functional level which has been achieved in the nursing home, and may have negative influence on the burden of care and quality of life of the patient and informal caregiver[22-24]. Eventually, permanent admission to a residential care facility or nursing home could become necessary. However, tailor-made multidisciplinary aftercare may prevent this and contribute to elderly stroke patients living independently in the community as long as possible.

To date, there is no effective aftercare programme available[25]. But research findings in the field of stroke aftercare suggest that adequate aftercare should include, after discharge, follow-up treatment in the patients' home environment which improves personal independence in daily living[26]. Furthermore, it should include strategies to

increase the skills to cope with the remaining physical, cognitive and/or psychosocial impairments, to improve social participation and to maintain functional level after rehabilitation[27]. Support for the informal caregiver is important to decrease the burden of care and improve quality of life.

Based on consideration of shortcomings in current stroke care for older stroke patients and the improvements as suggested in the literature, a multidisciplinary rehabilitation programme for older stroke patients is proposed. This paper presents the design of a multicentre trial evaluating a new multidisciplinary rehabilitation programme for older stroke patients admitted to a geriatric rehabilitation unit of a nursing home.

Objectives

The primary aim of this study is to evaluate the effect of this new rehabilitation pro-gramme on the level of daily activity, functional independence, perceived quality of life and social participation in elderly stroke patients as compared with usual care. In addition, the effect of the programme on the perceived care burden and quality of life of the informal caregiver is assessed.

The aim of the process evaluation is to gain insight into implementation fidelity, pro-gramme deliverance and the opinion of the stroke professionals, patients and informal caregivers about the programme. The aim of the economic evaluation is to assess the effects of the programme on health care utilisation and associated costs of elderly stroke patients.

Methods

Study design

The design of this study is a multicentre randomised controlled trial with patients allo-cated to either an intervention or control group. The study design is presented in figure 1. The study consists of an effect, process and economic evaluation, and will be carried out in the south of the Netherlands. Eight nursing homes with a specialised geriatric rehabilitation unit for stroke patients participated in this study.

The study and research protocol have been approved by the medical ethics committee of the university hospital Maastricht and Maastricht University (MUMC+), the Netherlands.

Study population

The study population consists of stroke patients and their primary informal caregivers. The inclusion of patients starts directly after the acute hospital phase. Patients are eli-

Inclusion criteria:

- Admission into one of the participating nursing homes for rehabilitation
- Stroke (medical diagnosis)
- ≥65 years
- Living independent before stroke
- Having the capability of living independent after discharge

Continuous registration of healthcare utilization

Continuous registration of healthcare utilization

Baseline measurements T0
After 1 week

Randomisation

Intervention group (128)   **Control group (128)**

Follow-up measurements T1
After 6 months

Follow-up measurements T2
After 12 months

Figure 1: Design of the study evaluating the multidisciplinary rehabilitation programme

gible to participate in the study when they meet the following inclusion criteria: admission to one of the participating geriatric rehabilitation units due to a recent stroke, aged 65 years or over, living independently in the community before a stroke, expected to be able to return home after discharge and giving informed consent to participate. The multidisciplinary teams of the participating units will check whether patients fulfil the inclusion criteria. The teams usually consist of a nursing home physician, a physiotherapist, an occupational therapist, a speech therapist and a psychologist. If the patient and the informal caregiver are unable to give informed consent, or the patient is medically

unstable and not able to start rehabilitation, the patient will be excluded. In addition, for every participating patient his/her primary informal caregiver is invited to participate in the study. A person is considered to be the primary informal caregiver in case the patient indicates him/her as the person mostly involved in informal and social care related activities on a long term basis.

Randomisation

The randomisation procedure is conducted by a research assistant, who is not involved in the geriatric rehabilitation care. Randomisation is performed based on a computerised block randomisation schedule (block size 8) to allocate eligible patients to the intervention or control group in each of the participating nursing homes. Participants allocated to the intervention group receive the multidisciplinary rehabilitation programme and participants allocated to the control group receive usual care.

Blinding

The participating nursing homes, patients, informal caregivers and the multidisciplinary teams who are participating in the study are not blinded for the treatment allocation. Research assistants involved in data collection and data analyses are blinded for treatment allocation.

Intervention

Description of the multidisciplinary rehabilitation programme for older stroke patients

<u>Organisation</u>
The rehabilitation programme consists of the following three care modules: 1) neurorehabilitation treatment for elderly stroke patients; 2) empowerment training for patient and informal caregiver; and 3) stroke education for patient and informal caregiver. The total programme, including all three modules, has a duration of between two and six months, depending on the individual problems of the patient and informal caregiver.
At the start of the programme an individual treatment plan is made including rehabilitation goals facilitating the transition from in- to outpatient rehabilitation care and to guide further rehabilitation at the patient's home. The individual patient's goals will be leading the treatment during both the in-patient and home-based rehabilitation. Rehabilitation goals during the total programme are formulated based on the Goal Attainment Scaling (GAS) method. GAS appeared to be an appropriate method as a guide for rehabilitation treatment for elderly people[28]. Both patient and informal caregiver receive a tailor-made treatment programme to improve their individual level of functioning. To evaluate the

treatment progress multidisciplinary team meetings will be organised every four to six weeks in the nursing home. To facilitate optimal communication and information distribution an electronic transmural patient record will be used.

The transmural stroke care coordinator
In order to facilitate the continuity of care, in the proposed programme a transmural stroke care coordinator is introduced as a new rehabilitation team member. He/she facilitates the transition of nursing home rehabilitation care services to community care by supporting the collaboration between the multidisciplinary stroke team of the nursing home and the community health services, namely community nurses, paramedical professionals and the general practitioner. After discharge, the coordinator conducts home visits, supports the general practitioner by organising multidisciplinary stroke team meetings and guides the patient and informal care giver in learning to apply self-management principles.

Module 1: neurorehabilitation treatment for elderly stroke patients
This module will focus on (re)learning the abilities needed for individual patients to function as independently as possible in their home environment. To optimise recovery, increase independence and check whether patients' home needs any modification before discharge, an occupational therapist and physical therapist will train the patients during guided home visits in their own home environment when they are still staying in the nursing home[29]. The care within this module is conducted by a multidisciplinary stroke team consisting of nursing home professionals, including a nursing home physician, a physiotherapist, an occupational therapist, a speech therapist, a psychologist and a transmural stroke coordinator. Besides treatment, this part of the programme includes all actions needed to ensure further aftercare, as well as activities to facilitate procedures for necessary home adaptations and assisting devices[30].

Module 2: empowerment training for patient and informal caregiver
This module begins after discharge to the home environment where the treatment focus will switch to learning to cope with residual impairments as a result of a stroke. Both patients and informal caregivers will be trained by the transmural stroke coordinator in improving their coping strategies and empowerment techniques based on self-management[27,31]. The care in this module will only be given by the professionals of the multidisciplinary team of the nursing home, who are involved in the treatment based on the individual needs of the patient. The transmural stroke coordinator coordinates care in collaboration with the general practitioner.

Module 3: stroke education for patient and informal caregiver

The last module is a stroke education course organised for patients and their informal caregivers. This course consists of four meetings with the focus on respectively the psychological and emotional consequences of stroke, perceived problems in living independently and returning to society and the new role of the healthy partner as caregiver. The module will be provided by a neuropsychologist, two volunteers of the Dutch Stroke Patient Association and Informal Caregivers Association and a social worker. The education course is organised in cooperation with the Dutch Stroke Patient Association and Informal Caregivers Association. In this part of the intervention the transmural stroke coordinator is responsible for inviting the patients and informal caregivers to the course.

Usual care

The usual care of elderly stroke patients after hospital discharge consists of a multidisciplinary neurorehabilitation programme in a nursing home. Most usual care programmes focus more on the needs of the patient than the informal caregiver. Usual care is provided by a multidisciplinary stroke team also containing a nursing home physician, a general practitioner, a physiotherapist, an occupational therapist, a speech therapist and a psychologist. A transmural stroke care coordinator is not involved. After discharge the follow-up care is provided separately by community services. The medical and paramedical information about the patient is distributed by letter. The main differences between the new programme and usual care are presented in table 1.

Table 1: Content differences between multidisciplinary rehabilitation programme and usual care

	Multidisciplinary transmural programme	Usual care
Care content		
• Multidisciplinary stroke team	+	+
• Care based on Dutch stroke guidelines	+	+
• Tailored approach with Goal Attainment Scaling	+	-
• Self-management	+	-
• Stroke education	+	-
• Home therapy during nursing home admission	+	-
• Multidisciplinary outpatient rehabilitation	+	-
• Home visits of transmural stroke care coordinator	+	-
Care organisation		
• Transmural stroke care coordinator	+	-
• Multidisciplinary team meetings in nursing home	+	+
• Multidisciplinary team meetings after discharge	+	-
• Electronic transmural patient record	+	-

Outcome measures

Effect evaluation

Primary outcome measures for patient

An overview of all outcome measurements per time point is presented in table 2. Primary outcome measures are daily activity measured by means of the Frenchay Activity Index (15-items activity scale)[32], functional dependence measured by means of the

Table 2: Primary and secondary outcome variables of the effect evaluation per time point

Outcome variables	Scale	No. of items	T0	T1	T2
Primary outcome variables (patient)					
Activity level after stroke	Frenchay Activity Index	15	FI	FI	FI
Level of functioning	Katz-15	15	FI	FI	FI
Quality of life (stroke specific)	Stroke Specific Quality of Life questionnaire	49	FI	FI	FI
Social participation	Impact on Participation and Autonomy (subscales autonomy outdoors and social life and relationships)	12	FI	FI	FI
Secondary outcome variables (patient)					
Perceived health	Question 1 and 2 RAND-36	2	FI	FI	FI
Mental wellbeing	RAND-36 (subscale mental wellbeing)	5	FI	FI	FI
Social functioning	Question 10 RAND-36	1	FI	FI	FI
Quality of life	Question 1 and 2 RAND-36 and a mark for quality of life	3	FI	FI	FI
Process questionnaire patient	-	24/15	-	FI	FI
Process questionnaire informal caregiver	-	21/14	-	SQ	SQ
Cost questionnaire	-	34	FI	FI	FI
Outcome variables (informal caregiver)					
Perceived care burden	Self-Rated Burden VAS and Carer QoL	10	SQ	SQ	SQ
Objective care load	Erasmus iBMG	4	SQ	SQ	SQ
Quality of life	Question 1 and 2 RAND-36 and a mark for quality of life	3	SQ	SQ	SQ
Perceived health	Question 1 and 2 RAND-36	2	SQ	SQ	SQ
Additional outcome measures					
Background characteristics patient	-	10/5/5	FI	FI	FI
Background characteristics informal caregiver	-	8/7/7	SQ	SQ	SQ
Cognitive functioning patient	Mini Mental State Examination	12	FI	-	-

T0 = at baseline, T1 = after 6 months, T2 = after 12 months, FI = face-to-face interview, SQ = self-report questionnaire

Katz-15 (15-items ADL and IADL scale)[33], perceived quality of life measured by means of the Stroke Specific Quality of Life scale (49-items stroke specific quality of life scale)[34] and social participation measured by means of two subscales (autonomy outdoors and social life and relationships) of the Impact on Participation and Autonomy (scale about participation in everyday life)[35].

Secondary outcome measures for patient

Secondary outcome measures are perceived health measured by question 1 and 2 of the RAND-36 (generic quality of life scale), mental wellbeing measured by subscale mental wellbeing of RAND-36, social functioning measured by question 10 of RAND-36 and quality of life measured by question 1 and 2 RAND-36 and a mark for quality of life.

Outcome measures related to informal caregiver

Outcome measures are the perceived care burden measured by means of the Self-Rated Burden VAS (care burden vas scale) and the Carer QoL (carer quality of life scale)[36], objective care burden measured by means of the Erasmus iBMG (4-items care burden scale)[37], quality of life and the perceived health both measured by question 1 and 2 of RAND-36 (including a mark for quality of life)[38].

Additional outcome measures

Besides the primary and secondary outcomes, the following background characteristics are measured in both patients and informal caregivers: age, gender, social economic status, ethnicity, level of education, marital status, living situation, travelling distance to patient and relationship with patient. In the participants cognitive functioning is also measured at baseline by means of the Mini Mental State Examination (12-items dementia scale)[39].

Process evaluation

In every participating nursing home a process evaluation will be conducted in order to study factors influencing the effectiveness and feasibility of the programme and to identify potential influencing factors that can facilitate future implementation of the intervention. The process evaluation will be based on the method suggested by Saunders et al.[40] with main evaluation themes: implementation fidelity, programme delivery and the opinions of the stroke professionals, patients and informal caregivers. First, implementation fidelity will be studied by evaluating the extent to which the implementation of the programme was performed as planned. Second, programme delivery is evaluated by checking whether rehabilitation care as provided by the stroke professionals has indeed been performed according to the study protocol. Third, satisfaction of the stroke

professionals, patients and informal caregivers with the programme is evaluated by assessing their opinion on various programme elements as performed.

Economic evaluation

The evaluation of the rehabilitation programme also involves a cost-effectiveness analysis in which we compare the programme costs and additional healthcare costs with those of usual care. The care utilisation is measured by continuously recording the volumes of health care utilisation consisting of costs for hospital admissions, structural admissions to a residential home, structural admissions to a nursing home, temporary admissions to a residential or nursing home, daytime treatment, day care, home care, mental healthcare service, social work, paramedical care and regular consultations with and visits from the general practitioner during a 12-month follow-up period.

Data collection

Data for the effect evaluation in patients will be assembled by face-to-face interviews based on a questionnaire (including all validated measurement instruments) and in the formal caregivers by self-administered questionnaires. Trained interviewers, who are blinded for group allocation, will conduct the interviews and self-administered questionnaires at baseline, after six months and after 12 months.

Data for the process evaluation from patients, informal caregivers and health professionals are assembled by self-administered questionnaires and registration forms. To evaluate the patients' and caregivers' opinions about the care they received, a research assistant will conduct a semi-structured interview with all patients and informal caregivers separately to evaluate the care they received and to describe their experience of the care received in the rehabilitation programme. Furthermore, to evaluate the professionals' opinions, a randomly selected representative sample of health care professionals will receive a questionnaire, which asks them about the programme being conducted in line with protocol, the possible reasons for deviations from protocol, the time invested, the bottlenecks identified and recommendations for improvement.

Furthermore, at the end of the intervention a focus group consisting of representatives of elderly stroke patients, informal caregivers, healthcare professionals and healthcare financiers will be organised to gather data about the implementation fidelity, programme deliverance and the opinions of the stroke professionals, patients and informal caregivers. Within the focus group semi-structured interview techniques will be used to discuss the questions about the rehabilitation programme as well as additional points raised by the participants. In order to check for contamination a selected sample of the electronic patient records will be analysed.

Data for the economic evaluation will be gathered by means of cost diaries, which are registered after six and 12 months. Healthcare costs are estimated according to the Dutch guideline for costs analyses in healthcare research[41].

Sample size calculation

Using data from earlier research based on the Frenchay Activity Index score as primary outcome variable[42], an assumed clinically relevant difference in activity level of two stroke populations is at least 3.5 with a standard deviation of 8.9. Based on a power of 0.8 and an alpha of 0.05, the study would need a sample size of 102 patients in each group. With a drop-out to follow-up estimated at approximately 25%, each group should include 128 participants. In total 256 participants are needed for the study.

Data analysis

The background characteristics of the participants will be described by using descriptive statistics. Baseline characteristics of the intervention and control group will be compared to detect differences at the start of the trial. Primary analyses of the effect data will be performed according to the intention-to-treat principle, including all participants with valid data on costs and clinical outcomes, regardless of whether they received the (complete) programme. Multiple regression analysis will be performed to calculate differences in the intervention and control group with regard to primary and secondary outcome measures. A per protocol subgroup analysis will be performed.

Data from the economic evaluation will be analysed to calculate cost-effectiveness and cost-utility ratios. Healthcare costs will be analysed by calculating incremental cost-effectiveness and cost-utility ratios. Data conducted from the process evaluation will be analysed by means of descriptive statistics and qualitative coding techniques. SPSS statistical software will be used for all analyses.

Progress of the study

Implementation of the study protocol and the inclusion of participants started in October 2010 and will continue until September 2012. Data will be collected until September 2013. The first results of the study will be available in 2014.

Discussion

This paper presents the study design of a multicentre randomised controlled trial to evaluate the effects and feasibility of a patient-tailored multidisciplinary rehabilitation programme for elderly stroke patients. The programme aims to improve care for

elderly stroke patients who are admitted to a nursing home for neurorehabilitation. This study will provide information about the effectiveness, process and costs of the new multidisciplinary rehabilitation programme and will give insight into how the care of elderly stroke patients might be improved. If this trial shows effectiveness and cost-effectiveness of the rehabilitation programme, the aim is to implement the intervention into the Dutch health care system.

Some methodological and practical limitations concerning the current study exist. However, the presented design is the most feasible method to conduct data to evaluate the effectiveness of the intervention.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors participated in the design of the study. TPV is the main researcher and responsible for writing the study protocol. TPV, JCH, JAV and JMS made the plan for the study and developed the intervention. TPV, JCH, JAV, EJK and JMS all contributed to the organisation of the trial. JCH is the project leader of the study. JCH and JAV are the co-supervisors of TPV. JMS is the supervisor of TPV. TPV, JCH, JAV, EJK and JMS contributed to the writing of the study protocol. All authors read and approved the final version of the manuscript.

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References

1. Weimar C, Kurth T, Kraywinkel K, Wagner M, Busse O, Haberl RL, Diener HC; German Stroke Data Bank Collaborators: Assessment of functioning and disability after ischemic stroke. *Stroke* 2002, 33(8):2053-9.

2. Mackay J, Mensah G: *Atlas of Heart Disease and Stroke*. Geneva: World Health Organization; 2004.

3. Vaartjes I, Dis I van, Visseren FLJ, Bots ML. Incidentie en prevalentie van hart- en vaatziekten in Nederland. In: Vaartjes I, van Dis I, Visseren FLJ, Bots ML: *Hart- en vaatziekten in Nederland 2010, cijfers over leefstijl- en risicofactoren, ziekte en sterfte*. Den Haag: Nederlandse Hartstichting, 2010.

4. Gommer AM (RIVM), Poos MJJC (RIVM): *Beroerte: prevalentie, incidentie en sterfte naar leeftijd en geslacht. Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid*. Bilthoven: RIVM, 2011.

5. Schols JMGA, Crebolder HFJM, Van Weel C: Nursing Home and Nursing Home Physician: The Dutch Experience. *JAMDA* 2004, 5(3):207-212.

6. Eyck A, Peerenboom PB: *Revalidatie in Nederland. De grenzen van AWBZ en ZVW.* Leusden: ETC TANGRAM; oktober 2006.

7. Landelijke Medische Registratie (PRISMANT), 2004

8. Huijsman R, Klazinga NS, Scholte op Reimer WJM, Van Wijngaarden JDH, Van Exel NJA, Van Putte-Boon C, Prestholt FT, Koopmanschap MA, Niessen LW: *Results of the EDISSE study of three regional experiments with stroke services.* Report ZonMW, 2001.

9. Lincoln NB, Gladman JR, Berman P, Noad RF, Challen K: Functional recovery of community stroke patients. *Disabil Rehabil* 2000, 22(3):135-9.

10. Desrosiers J, Noreau L, Rochette A, Bravo G, Boutin C: Predictors of handicap situations following post-stroke rehabilitation. *Disabil Rehab* 2002, 24(15):774-85.

11. Dijkerman HC, Wood VA, Hewer RL: Long-term outcome after discharge from a stroke rehabilitation unit. *J R Coll Physician Lond* 1996, 30(6):538-46.

12. Peerenboom PBG, Spek J, Zekveld I, Cools HJM., Balen R van, Hoogenboom MJ: *Revalidatie in de AWBZ, omvang, aard en intensiteit*. ETC Tangram/LUMC; 2008.

13. Cramer SC: Changes in motor system function and recovery after stroke. *Restor Neurol Neurosci* 2004, 22(3-5):231-38.

14. D'Alisa S, Baudi S, Mauro A, Miscio G: How does stroke restrict participation in long-term post-stroke survivors? *Acta Neurol Scand* 2005, 112(3):157-62.

15. Murray J, Ashworth R, Forster A, Young J: Developing a primary care-based stroke service: A review of the qualitative literature. *Br J Gen Pract* 2003, 53(487):137-42.

16. Morrison V, Pollard B, Johnston M, MacWalter R: Anxiety and depression 3 years following stroke: demographic, clinical, and psychological predictors. *J Psychosom Res* 2005, 59(4):209-13.

17. Rasquin SM, Lodder J, Ponds RW, Winkens I, Jolles J, Verhey FR: Cognitive functioning after stroke: A one-year follow-up study. *Dement Geriatr Cogn Disord* 2004, 18(2):138-44.

18. van Heugten C, Visser-Meily A, Post M, Lindeman E: Care for carers of stroke patients: evidence-based clinical practice guidelines. *J Rehabil Med* 2006, 38(3):153-8.

19. Bollars S, van Erp J, Fens M, van Gorp E, van Hoppe J, Krikke T, de Meris, J, Notz B, van der Ven A, Vluggen T, Benjaminsen S: *Uitbehandeld! Hoezo? Een leidraad in het doolhof van zorg in de chronische fase na een CVA*. Kennisnetwerk CVA Nederland; 2012.

20. Bull MJ: Managing the transition from hospital to home. *Qualitative Health Res* 1992, 2:27-41.

21. Cott CA, Wiles R, Devitt R: Continuity, transition and participation: preparing clients for life in the community post-stroke. *Disabil Rehabil* 2007, 29(20-21):1566-74.

22. Boter H, Rinkel GJ, de Haan RJ: HESTIA Study Group. Outreach nurse support after stroke: a descriptive study on patients' and carers' needs, and applied nursing interventions. *Clin Rehabil* 2004, 18(2):156-63.

23. Turner-Stokes L, Hassan N: Depression after stroke: a review of the evidence base to inform the development of an integrated care pathway. Part 1: Diagnosis, frequency and impact. *Clin Rehabil* 2002, 16(3):231-247.

24. Landi F, Onder G, Cesari M, Zamboni V, Russo A, Barillaro C, Bernabei R; The Silvernet-HC study group: Functional decline in frail community-dwelling stroke patients. *Eur J Neurol* 2006, 13(1):17-23.

25. Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF: Therapy-based rehabilitation services for patients living at home more than one year after stroke. *Cochrane Database Syst Rev* 2008, 16(2):CD005952.

26. Outpatient Service Trialists: Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database Syst Rev* 2003, (1):CD002925

27. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR: Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care* 2001, 39(11):1217-23.

28. Rockwood K, Stolee P, Fox R: Use of goal attainment scaling in measuring clinically important change in the frail elderly. *J Clin Epidemiol* 1993, 46(10):1113-18.

29. Walker MF, Leonardi-Bee J, Bath P, Langhorne P, Dewey M, Corr S, Drummond A, Gilbertson L, Gladman JR, Jongbloed L, Logan P, Parker C: Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. *Stroke* 2004, 35(9):2226-32.

30. Fjaertoft H, Indredavik B, Lydersen S: Stroke unit care combined with early supported discharge: long-term follow-up of a randomized controlled trial. Stroke 2003, 34(11):2687-91.

31. Jones F: Strategies to enhance chronic disease self-management: how can we apply this to stroke? *Disabil Rehabil* 2006, 28(13-14):841-847.

32. Schuling J, de Haan R, Limburg M, Groenier KH: The Frenchay Activities Index. Assessment of functional status in stroke patients. Stroke 1993, 24(8):1173-7.

33. Weinberger M, Samsa GP, Schmader K, Greenberg SM, Carr DB, Wildman DS: Comparing proxy and patients' perceptions of patients' functional status: results from an outpatient geriatric clinic. *J Am Geriatr Soc* 1992, 40(6):585-8.

34. Williams LS, Weinberger M, Harris LE, Biller J: Measuring quality of life in a way that is meaningful to stroke patients. *Neurology* 1999, 53(8):1839-43.

35. Cardol M, de Haan RJ, van den Bos GA, de Jong BA, de Groot IJ: The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clin Rehabil* 1999, 13(5):411-9.

36. Brouwer WB, van Exel NJ, van GB, Redekop WK: The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. *Qual Life Res* 2006, 15(6):1005-21.

37. van den Berg B, Spauwen P: Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health Econ* 2006, 15(5):447-60.

38. van der Zee K, Sanderman R: *Het meten van de algemene gezondheidstoestand met de rand-36, een handleiding*; 2002.

39. Folstein MF, Folstein SE, McHugh PR: Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975, 12(3):189–98.

40. Saunders RP, Evans MH, Joshi P: Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. *Health Promot Pract* 2005, 6(2):134-47.

41. Oostenbrink AM, Koopmanschap MA, Rutten FFH: *Handleiding voor kostenonderzoek, methoden en standaard kostprijzen voor economische evaluaties in de gezondheidszorg.* College voor zorgverzekeringen; 2004.

42. Schuling J, de Haan R, Limburg M, Groenier KH: The Frenchay Activities Index. Assessment of functional status in stroke patients. *Stroke* 1993, 24(8):1173-7.

CHAPTER 5

Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial

Background

Almost half of the stroke patients admitted to geriatric rehabilitation has persisting problems after discharge. Currently, there is no evidence based geriatric rehabilitation programme available for older stroke patients, combining inpatient rehabilitation with adequate ambulatory aftercare in the community. Therefore, we developed an integrated multidisciplinary rehabilitation programme that includes aftercare for older persons with stroke. We evaluated the effectiveness of this newly developed rehabilitation programme in comparison to usual care.

Methods

A multicentre randomised controlled trial was conducted in eight geriatric rehabilitation stroke units and their collaborating partners in primary care. The study population involved stroke patients and their informal caregivers who were aged 65 or over, living in the community before admission to geriatric rehabilitation, and expected to be able to return home after discharge. The programme consisted of three modules: inpatient neurorehabilitation, home-based self-management training, and stroke education. For patients, daily activity (FAI) was assessed as primary outcome and functional dependence (Katz-15), perceived quality of life (SSQoL) and social participation (IPA) as secondary outcomes. Additionally, among informal caregivers perceived care burden (self-rated burden VAS), objective care burden (Erasmus iBMG), and quality of life (CarerQol), were assessed as secondary outcomes.

Results

In total 190 patients and 172 informal caregivers were included. Mean age of the patients in the intervention group was 78.9 years (SD= 7.0) and in the usual care group 79.0 years (SD=6.5). Significant favourable effects for the programme were observed for the subscale autonomy outdoors of the IPA (-2.15, P=.047, and for the informal caregivers perceived care burden (1.23, P=.048. For the primary outcome daily activity and the other secondary outcomes, no significant effects were observed.

Conclusion

The integrated multidisciplinary programme had no effect on daily activity of older stroke patients. However, patients participating in the programme had a higher level of perceived autonomy of outdoor activities and their informal caregivers perceived a lower care burden. The programme might be promising in providing adequate (after)care, although adaptation of the programme is recommended to increase its feasibility and improve its effects.

Trial registration: Current Controlled Trials ISRCTN62286281. Registered 19-3-2010.

Keywords: Stroke, Geriatric rehabilitation, Elderly persons, Randomised controlled trial, Aftercare

Abstract

Background

Stroke is one of the leading causes of death and a major cause of disability worldwide. Because of the aging population stroke is highly prevalent and can have a major impact on daily functioning and quality of life[1,2].

In the Netherlands, each year about 40% of the older persons who suffer from acute stroke are admitted to an intermediate care facility for geriatric rehabilitation after a period of hospitalisation[3-5]. About half of the older stroke patients who are discharged home after geriatric rehabilitation still experience serious impairments in daily functioning and social participation, caused by severe cognitive and functional incapacities[6] . In patients who are socially inactive and are lacking appropriate coping skills, these impairments can lead to a substantial decrease in quality of life and depression[7]. Most older persons who are admitted to geriatric rehabilitation have multimorbidity that can interfere with rehabilitation and therefore may influence outcomes negatively. Besides a negative impact on patients, stroke and multimorbidity may also increase the burden of care perceived by informal caregivers which may also result in a decrease in their quality of life[7,8]. Eventually, when the burden for the informal caregiver becomes too high, this may result in permanent admission of the patient to a long-term care facility.

In the Netherlands, stroke care for older patients is organised in stroke services aiming to realise more integrated care. This trend has led to a reduction in mortality, a decrease in admissions to long-term institutional care, more satisfaction among patients and caregivers, and more cost-effectiveness[9]. Although stroke care has achieved these quality improvements, sufficient aftercare after inpatient geriatric rehabilitation is often lacking in usual care, or when available, is too fragmented which makes it difficult to support patients and their informal caregivers in dealing with stroke related problems at home after discharge from rehabilitation.

Therefore, it seems important that older stroke patients and their caregivers, receive a rehabilitation treatment that includes tailor-made aftercare after discharge from geriatric rehabilitation to facilitate the transition to the home situation and to support patients and their caregivers in coping with the patients' residual impairments in daily life. Training older patients and their caregivers in effective coping skills to manage their impairments might contribute to living independently in the community and staying socially active as long as possible. In addition, adequate aftercare may prevent negative long-term consequences such as decrease in daily activity level, depression and postpone admission to a long-term care facility[10,11]. Therefore, stroke rehabilitation should include structural follow-up treatment in the patients' home environment to improve

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functional independence of patients, to train patients in coping strategies to increase the adaptation skills to manage the remaining physical, cognitive and/or psychosocial impairments and improve quality of life, and to provide support for the informal care-giver to decrease the burden of care[12,13].

Currently, there is no effective and well-organised aftercare programme available for older stroke patients admitted to geriatric rehabilitation[14]. Therefore, we developed an integrated multidisciplinary geriatric rehabilitation programme that includes aftercare for older persons with stroke. It aims to facilitate early discharge if possible, to train patients and informal caregivers to cope with the residual impairments by enhancing self-management, to optimise the level of participation after rehabilitation, and to provide support at home after discharge from rehabilitation.

The aim of this study was to evaluate the effects of this integrated programme as com-pared with usual care on the primary outcome daily activity level, and on the secondary outcomes functional independence, perceived quality of life and social participation of patients, and perceived care burden, objective care burden, and quality of life of their informal caregivers.

Methods

Study design
The design of this study was a two-arm multicenter randomised controlled trial with patients allocated to either the integrated programme or usual care. The study was conducted in eight geriatric rehabilitation units for patients with stroke. More specific information about the methodology of the study can be obtained from protocol article published earlier[15]. This study adheres to CONSORT guidelines for Randomized Con-trolled Trials. The protocol of this study was registered with the International Standard Randomised Controlled Trial Register Number (ISRCTN62286281), and The Dutch Trial Register (NTR2412).

Study population
The study population involved stroke patients and their informal caregivers who were admitted to one of the eight participating geriatric rehabilitation stroke units after hos-pital discharge. The study population was restricted to patients aged 65 or over, living in the community before admission to geriatric rehabilitation, and expected to be able to return home after discharge. Inclusion started directly after admission to the geriatric rehabilitation unit. At admission the rehabilitation team under the responsibility of an

elderly care physician, conducted a comprehensive geriatric assessment based on the Dutch Stroke guidelines to determine if the patient was expected to return home after discharge. The assessment includes measurements such as: age, sex, socio-economic status, risk factors, co-morbidity, stroke location and stroke severity measured by the National Institute of Health Stroke Scale, Barthel Index, Frenchay Activity Index, Modified Rankin Scale, Stroke Adapted Sickness Impact Profile 30, Mini Mental State Examination, Apraxia Test, Star Cancellation Test, Hospital Anxiety and Depression Scale and Caregiver Strain Index. Based on this assessment (in combination with the other eligibility criteria), patients were included in the study. Patients who did not give informed consent for participation, or were medically unstable and thereby not able to start rehabilitation, were excluded. In addition, the primary informal caregiver of each participating patient was invited to participate in the study. A person is considered to be the primary informal caregiver in case the patient indicates him/her as the person mostly involved in informal care activities for this patient. The multidisciplinary teams of the participating geriatric rehabilitation units received a three hour training which included the important key elements of the intervention protocol. During the study, the participating multidisciplinary teams were responsible for checking which admitted patients fulfilled the inclusion criteria of the study. To calculate the sample size, data from earlier research was used. Based on the Frenchay Activity Index score as primary outcome variable[16], the assumed clinically relevant difference in activity level of two stroke populations had to be at least 3.5. Based on a power of 0.8 and an alpha of 0.05, the study would need a sample size of 102 patients in each group. With an expected drop-out during follow-up estimated at approximately 25%, each group should include 128 participants. In total 256 participants were needed for the study.

Randomisation

After inclusion, all patients and their informal caregivers of each participating nursing stroke unit were randomised on patient level by an independent research assistant. The randomisation procedure was conducted by a computerised block randomization schedule using IBM SPSS software version 19.0 (10 patients per block) to allocate the included patients to the intervention or usual care group. Patients allocated to the intervention group received the integrated programme and patients allocated to the usual care group received care as usual. Data were collected by research assistants who were blinded for treatment allocation. Because of study characteristics, blinding of patients, informal caregivers and care professionals involved was not possible.

Integrated multidisciplinary geriatric rehabilitation programme

Organisation of the integrated programme
The integrated programme consisted of three care modules; 1) inpatient neuroreha-bilitation treatment; 2) home-based self-management training for patient and informal caregiver; and 3) stroke education for patient and informal caregiver. Table 1 presents both the integrated multidisciplinary geriatric programme and usual care.

The treatment progress was evaluated in monthly multidisciplinary team meetings for every individual patient. All communication and information by the care professionals about the patient and informal caregiver was conducted by using a shared electronic patient record, which was specifically developed for this study. To optimise care by fa-cilitating faster discharge and to give support after discharge a stroke care coordinator was introduced in all participating rehabilitation teams. The total programme duration, including all three modules, varied between 2 to 6 months, depending on the care needs of the patient. All care professionals of the participating stroke teams were trained in conducting the programme according to protocol[15].

The stroke care coordinator
When the patient was admitted to the geriatric rehabilitation unit, the stroke care coor-dinator was introduced. The stroke care coordinator facilitated the transition of nursing home rehabilitation care services to community care by supporting the collaboration

Table 1: Integrated multidisciplinary geriatric rehabilitation programme and usual care

	Integrated programme	Usual care
Care content		
Multidisciplinary stroke team	+	+
Care based on Dutch stroke guidelines	+	+
Tailored approach with Goal Attainment Scaling	+	-
Self-management	+	-
Stroke education	+	-
Home therapy during nursing home admission	+	-
Multidisciplinary outpatient rehabilitation	+	-
Home visits of stroke care coordinator	+	-
Care organisation		
Stroke care coordinator	+	-
Multidisciplinary team meetings in nursing home	+	+
Multidisciplinary team meetings after discharge	+	-
Electronic patient record	+	-

between the multidisciplinary stroke team of the nursing home and the community health services, namely community nurses, paramedical professionals and the general practitioner. After discharge, the coordinator conducted home visits, supports the general practitioner by organising multidisciplinary stroke team meetings and guided the patient and informal care giver in learning to apply self-management principles.

At the start of geriatric rehabilitation, the coordinator had an introduction meeting with both the patient and informal caregiver. In this meeting, the coordinator provided general information about the rehabilitation programme. Furthermore, during the rehabilitation process the coordinator facilitated the transition of the patient from inpatient geriatric rehabilitation care to home-based care by supporting the collaboration between the multidisciplinary stroke team of the geriatric rehabilitation unit, community health services and general practitioner. After discharge, the coordinator conducted at least two home visits, organised multidisciplinary stroke team meetings in the community and supported the patient and informal caregiver in practicing self-management skills at home.

Module 1: inpatient neurorehabilitation treatment for patients
The first module focused on (re)learning the abilities needed for individual patients to function as independently as possible in their own home environment. At the start of this module, an individual treatment plan was made together with the patient including the development of rehabilitation goals facilitating the transition from in-patient to home-based rehabilitation care and to guide further rehabilitation at the patient's home.

To make rehabilitation goals more measurable during inpatient rehabilitation, the principles of the Goal Attainment Scaling (GAS) method were used. GAS is a methodology, which is shown to be appropriate for developing rehabilitation goals among older persons[16]. To facilitate transition to the home environment, during the stay at the geriatric rehabilitation unit, an occupational or physical therapist, depending on the rehabilitation goals, trained with the patients at least twice in their own home environment. These training sessions were done to optimise recovery, to train specific functional skills at home to increase independence, and to check if any home adjustments were needed before discharge. The training programme within this module was conducted by a multidisciplinary stroke team consisting of professionals working at the geriatric rehabilitation unit of the nursing home. The stroke rehabilitation team included an elderly care physician, a physical therapist, an occupational therapist, a speech therapist, a (neuro) psychologist and a stroke coordinator.

Module 2: home-based self-management training for patient and informal caregiver
The second module started directly after discharge to the home environment. Treatment focused on learning to cope with residual cognitive and functional impairments as a result of stroke. The stroke care coordinator trained patients and caregivers to improve their coping strategies and empowerment techniques. This training which included formulating rehabilitation goals for the patients and making action plans, were based on the basic principles of self-management and aimed to increase problem-solving skills and participation[13,17]. If necessary, patients could still receive ambulatory follow-up rehabilitation treatment by a physical or occupational therapist, with the intention that at least half of the treatment sessions should take place in the patient's home. If home treatment was not possible, the patient could receive this treatment in a day care facility or private therapy practice. The training in this module was also provided by the professionals of the regional multidisciplinary team consisting of professionals of the geriatric rehabilitation unit and community health care.

Module 3: stroke education for patient and informal caregiver
The third module was a short stroke education course for patients and their involved informal caregivers. The course consisted of four education sessions of two hours each with the focus on respectively the psychological and emotional consequences of stroke, perceived problems during independent living and participation in societal activities, and on the role of the informal caregiver. The course was provided by a (neuro)psychologist, two volunteers of the Dutch Stroke Patient Association and Informal Caregivers Association, and a social worker. The stroke coordinator invited the patients and informal caregivers to participate in the course. In two of the four meetings patients and informal caregivers were divided in two separate groups, to provide them the opportunity to express their problems and concerns more freely and share experiences with other patients/caregivers.

Usual care
In the Netherlands, usual care for older people with a stroke that need inpatient-rehabilitation consists of multidisciplinary neurorehabilitation on a geriatric rehabilitation unit. After discharge, there is in general no coordinated multidisciplinary aftercare for patient and informal caregiver. Most care programs vary in content and are in general more focused on the recovery of the patient and limited on the needs of the informal caregiver. After discharge, the follow-up care is usually provided by monodisciplinary community services, with no multidisciplinary approach. In general, there is no additional involvement anymore of the stroke rehabilitation team of the geriatric rehabilitation unit.

Measurements

Background characteristics
The following background characteristics were measured in both patients and informal caregivers: age, sex, level of education, marital status, living situation, and relationship between patient and informal caregiver. In addition, cognitive functioning of patients was measured at baseline by means of the Mini Mental State Examination (consisting of 11-items, range 0-30 with higher scores indicating better functioning)[18-20].

Primary outcome measure
An overview of the primary and secondary outcome measurements per time point is presented in table 2. Primary outcome measure was *daily activity* of patients measured by means of the Frenchay Activity Index (FAI) a 15-items activity scale (range 15-60 with higher scores indicating better functioning)[21]. The outcome of the FAI at baseline (i.e. at admission to the geriatric rehabilitation unit) was based on the activity level of patients

Table 2: Overview of all outcome measures per time point

Subject	Outcome measures	Measurement scale	Number of items	Time point		
				T0	T1	T2
Patient	*Primary outcome measure*					
	Activity level after stroke	Frenchay Activity Index	15	FI	FI	FI
	Secondary outcome measures					
	Level of functioning	Katz-15	15	FI	FI	FI
	Stroke specific quality of life	Stroke Specific Quality of Life Questionnaire	49	FI	FI	FI
	Social participation	Impact on Participation and Autonomy (subscales autonomy outdoors and social life and relationships)	12	FI	FI	FI
Informal caregiver	*Secondary outcome measures*					
	Perceived care burden	Self-Rated Burden VAS	10	SQ	SQ	SQ
	Carer Quality of life	Carer Qol	7	SQ	SQ	SQ
	Objective care load	Erasmus iBMG	4	SQ	SQ	SQ
	Background characteristics					
	Background characteristics patient	-	10/5/5	FI	FI	FI
	Background characteristics informal Caregiver	-	8/7/7	SQ	SQ	SQ
	Cognitive functioning patient	Mini Mental State Examination	11	FI	-	-

T0 = at baseline, T1 = after 6 months, T2 = after 12 months, FI = face-to-face interview, SQ = self-report questionnaire.

3 months before stroke occurred, as estimated by the patient. Follow-up measurements of the FAI were conducted after 6 and 12 months of follow-up.

Secondary outcome measures

Secondary outcome measures for patients were *functional dependence* measured by the Katz-15 (consisting of 15 items (range 0-15 with lower scores indicating a higher level of independence)[22], *perceived quality of life* measured by the Stroke Specific Quality of Life scale (SSQoL) a 49-items quality of life scale which contains two subscales "Physical functioning" consisting of 27 items (range 27-135) and "Psychosocial functioning" consisting of 22 items (range 22-110). For both subscales of the SS-QOL, a lower score indicates a lower perceived quality of life[23]. The outcome measure *social participation* was measured by two subscales "Autonomy outdoors" consisting of 5 items (range 0-20) and "Social relations" consisting of 7 items (range 0-28)) of the Impact on Participation and Autonomy (IPA)[24]. For both IPA subscales a lower score indicates a better participation level. The other subscales of the IPA were excluded because of the overlap with items of the FAI, Katz-15, and SSQoL. The Katz-15, IPA, and SSQol were measured at admission to the geriatric rehabilitation unit, and after 6 and 12 months of follow-up.

Secondary outcome measures in informal caregivers involved the perceived care burden measured by means of the Self-Rated Burden VAS scale (10 points likert scale with lower scores indicating less care burden) and the Carer Quality of Life scale (7 items with lower scores indicating less care burden)[25], *objective care burden* measured by means of the Erasmus iBMG (4-items care burden scale; item 1 "time spent on helping patient with ADL-activities", item 2 "time spent on helping patient with personal care", item 3 "time spent on helping patient with moving outside", item 4 "time spent by other informal caregivers or volunteers on helping patient")[26]. The total amount of time spent on the four items indicates the dependence of help by the informal caregiver. All secondary outcome measures were measured at admission to the geriatric rehabilitation unit, and after 6 and 12 months of follow-up.

Data collection

Data for the effect evaluation was collected by face-to-face interviews among patients and self-reported questionnaires among informal caregivers (see table 2). Research assistants conducted the interviews in the geriatric rehabilitation unit and at the patient's home and provided the self-administered questionnaires to caregivers at baseline, after 6 months and after 12 months. All data was gathered between 2010 and 2015.

Statistical Analyses

Background characteristics of the patients and informal caregivers were checked for meaningful imbalance, analysed and described by using descriptive statistics. Analyses

of the difference between primary and secondary outcomes for intervention group and usual care group were performed according to the intention-to-treat principle (with possible covariates taken into account in case of observed imbalance in baseline characteristics),including all valid data of all available participants, regardless of whether they received the (complete) programme. A two-level linear regression analysis was performed to calculate differences between the intervention and usual care group with regard to primary and secondary outcome measures. In the analyses level one was the repeated measures and level two was the patients. In all analyses, P=< .05 was considered statistically significant. All statistical analyses were conducted using IBM SPSS software version 25 for Windows by a researcher who was blinded for treatment allocation.

Ethics
The medical ethics committee of Maastricht University Medical Centre (MUMC+), the Netherlands, approved this study.

Results

Background characteristics

Table 3 shows the background characteristics of patients and informal caregivers. In total 190 patients (mean age: 78.9 years) and 172 informal caregivers (mean age: 60.8 years) were included. Of these 190 patients 99 patients were randomised to the intervention group and 91 patients to the usual care group. Figure 1 shows the flowchart of the patient sample.

Of the 172 informal caregivers 90 were randomised to the intervention group and 82 to the usual care. In both groups most informal caregivers were female. More than half of the patients lived alone, and the most common relationship between informal caregiver and the patient was a parent-child (in law) relationship. The analyses showed only an imbalance in sex (this outcome measure was included as a covariate), but further no meaningful imbalance between all other outcome measures of the intervention and usual care group at baseline (see appendix: Baseline characteristics of patients checked on statistical differences at baseline).

Table 3: Baseline characteristics of patients and informal caregivers

| Baseline characteristics	Scores (N)	
Patients (N=190)	*Intervention group (N=99)*	*Usual care group (N=91)*
Background characteristics		
Mean age (SD)	78.9 (7.0)	79.0 (6.5)
Female sex N (%)	69 (69.7)	46 (51.1)
Mean cognitive status (MMSE) (SD)	21.9 (5.2)	22.0 (4.1)
Maried with a partner N (%)	39 (40)	43 (47)
Living situation		
• Independent alone N (%)	53 (54.0)	43 (47.3)
• Independent with others N (%)	45 (45.5)	47 (51.6)
Outcome measurement at baseline	**Observed mean (SD)**	
Primary outcome		
Frenchay Activity Index (FAI)	40.2 (8.8)	38.8 (7.3)
Secondary outcome		
Impact on Participation and Activity (IPA)		
• Autonomy outdoors	15.4 (4.4)	14.8 (4.3)
• Relationship	15.3 (3.9)	15.8 (3.1)
Katz-15	6.0 (4.0)	6.5 (3.3)
Stroke Specific Quality of Life (SSQoL)		
• Subscale physical functioning	99.6 (20.8)	97.1 (21.3)
• Subscale psychosocial functioning	77.2 (16.8)	76.2 (16.9)
Informal caregivers (N=172)	*Intervention group (N=90)*	*Usual care group (N=82)*
Background characteristics		
Mean age (SD)	61.0 (13.5)	60.5 (13.5)
Female sex N (%)	53 (64.6)	58 (70.7)
Relationship with patient		
Husband, wife, life partner N (%)	28 (31.1)	32 (39.0)
Sister, brother, brother in law, sister in law N (%)	3 (3.3)	5 (6.1)
Daughter (in law), son (in law) N (%)	56 (62.2)	40 (48.8)
Other N (%)	3 (3.3)	5 (6.1)
Outcome measurement at baseline	**Observed mean (SD)**	
Carer Quality of Life	85.9 (12.7)	82.5 (14.7)
Erasmus iBMG (time spended on helping patient)		
Item 1: helping patient with ADL-activities	0.5 (0.4)	0.5 (0.4)
Item 2: helping patient with personal care	0.8 (0.3)	0.8 (0.4)
Item 3: helping patient with moving outside	0.5 (0.4)	0.5 (0.4)
Item 4: help by other informal caregivers or volunteers	0.7 (0.4)	0.7 (0.4)
Self-Rated Burden VAS	4.0 (2.4)	4.3 (2.4)

CONSORT flow diagram of the trial
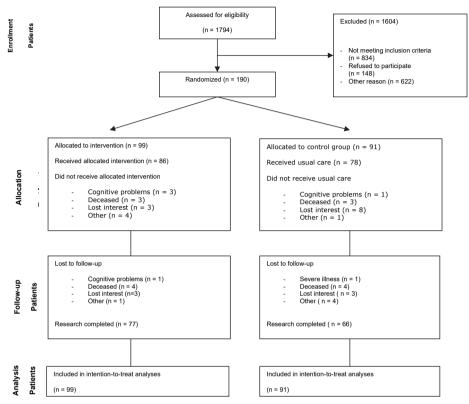
Figure 1: flowchart of patients through the study

Effects of the integrated programme

Patients

Results of the two-level multilevel analysis on patient level are presented in table 4. The results show that the intervention had no effect on the primary outcome daily activity as measured with the FAI (-1.69, p=.368).

The analyses did show a significant favourable effect for the intervention on the subscale "Autonomy outdoors" of the IPA scale (-2.15, p= .047). All other secondary outcome measures i.e. subscale "Social relations" of the IPA scale (.60, p=.560), Katz-15 questionnaire (-.69, p=.372), subscale "Physical functioning" of the SSQoL scale (3.08, p=.476), and the subscale "Psychosocial functioning" of the SSQoL scale (8.45, p= .054) showed no significant effects.

Table 4: Effects on primary and secondary outcomes in patients

Variable	6 months follow-up observed mean (SD)		Group effect	P-value	95% CI	ICC
Primary outcome						
	Intervention group	Usual care group				
Frenchay Activity Index (FAI)	29.7 (8.9)	29.1 (9.1)	-1.69	.368	-5.39 – 2.00	.74
Secondary outcomes						
Impact on Participation and Activity (IPA)						
• Autonomy outdoors	14.2 (4.1)	14.6 (4.2)	-2.15	.047	-4.27 – -.03	.55
• Social relations	15.2 (3.4)	16.0 (4.1)	.60	.560	-1.43 – 2.63	.41
Katz-15	5.9 (3.5)	6.0 (4.0)	-.69	.372	-2.22 - .83	.69
Stroke Specific Quality of Life (SSQoL)						
• Subscale physical functioning	102.2 (19.9)	99.2 (22.5)	3.08	.476	-5.41 – 11.56	.71
• Subscale psychosocial functioning	81.3 (17.1)	78.7 (18.0)	8.45	.054	-.14 – 17.03	.64

Informal caregivers

Table 5 presents the results of the effect of the intervention on the informal caregiver. The results show that the intervention had a significant favourable effect on the Self-Rated Burden vas scale (1.23, p=.048), but no effects on the other outcome measures Carer Quality of Life questionnaire (3.54, p=.323), and Erasmus iBMG; item 1) helping patient with ADL-activities (.09, p=.447), item 2) helping patient with personal care (.09, p=.380), item 3) helping patient with moving outside (-.03, p=.784), item 4) help by other informal caregivers of volunteers (.03, p=.767).

Table 5: Effects on the outcomes in informal caregivers

Variable	6 months follow-up observed mean (SD)		Group effect	P-value	95% CI	ICC
	Intervention group	Usual care group				
Carer Quality of Life	85.3 (11.6)	82.9 (13.9)	3.54	.323	-3.50 – 10.58	.41
Erasmus iBMG (time spended on helping patient)						
Item 1: helping patient with ADL-activities	0.4 (0.4)	0.4 (0.4)	.09	.447	-.15 – .34	.49
Item 2: helping patient with personal care	0.8 (0.4)	0.8 (0.4)	.09	.380	-.12 – .30	.44
Item 3: helping patient with moving outside	0.4 (0.3)	0.5 (0.4)	-.03	.784	-.25 – .19	.38
Item 4: help by other informal caregivers or volunteers	0.6 (0.4)	0.6 (0.4)	.03	.767	-.18 – .24	.55
Self-Rated Burden VAS	4.3 (2.3)	4.0 (2.0)	1.23	.048	-.02 – 2.48	.43

Discussion

The results of this study show that the integrated multidisciplinary geriatric rehabilitation programme for older patients with stroke had no significant effect on the primary outcome daily activity as compared to usual care. With regard to the secondary outcomes, the programme showed favourable effects on the patients' outdoor autonomy and the perceived care burden of their informal caregivers. For the other secondary outcomes, no significant intervention effects were observed.

The lack of effect of the programme on daily activity and most secondary outcome measures might be explained by several reasons. First, the process evaluation which was performed alongside the trial, revealed that part of patients and informal caregivers did not receive all key elements of the programme[27]. Although almost all patients formulated rehabilitation goals, the GAS method was only used among two thirds of the patients. In addition, the percentage of therapy sessions performed in the patients' home environment was lower than planned, and only about a quarter of the patients and informal caregivers attended the education sessions. Furthermore, the self-management training was considered by the care professionals as rather complex and difficult to apply for frail older persons, because it was complicated for the patients to develop and carry out action plans by themselves[27]. As it is widely recognised that in complex interventions often not all aspects of the intervention are completely performed according to protocol and that adaptation to local circumstances may be necessary[28], it is important to improve the feasibility of the integrated programme by tailoring the goal attainment scaling, self-management training and education sessions more optimally to the population of frail older stroke patients[27]. In addition the training of care professionals in conducting the programme could be improved. However, despite this, the majority of patients, informal caregivers and care professionals indicated the beneficial aspects of the programme [27].

Second, a review of Fens and colleagues[29] performed in 2013 evaluating the effectiveness of multidisciplinary interventions for stroke patients living in the community after being discharged home after hospitalization or inpatient rehabilitation, showed that none of the 11 studies that assessed daily activities reported a favourable effect of the intervention on this outcome. Although these multidisciplinary interventions included different combinations of elements, it clearly shows that improving daily activity among community living stroke patients is very complex, which is also confirmed by the results of our trial.

Based on our results, the increased level of autonomy outdoors of the patients receiving the programme, seems to indicate that despite the lack of increase in the actual

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frequency of daily activity as measured by the FAI, the level of (outdoor) activities is more in accordance with the needs and wishes of the patients. An explanation for this finding could be that the self-management component of the programme may have improved the coping skills of patients and their informal caregivers, and helped them to have more realistic expectations about the patients' outdoor activities. The increase in autonomy related to outdoor activities, is an important finding, as De Graaf and colleagues emphasised the need to pay more attention to the social participation of stroke survivors aged over 70 years, since more restrictions in participation were perceived in comparison to younger stroke survivors one year after stroke[30]. Furthermore, increased attention for participation may also contribute to preventing depressive symptoms after stroke[31].

With regard to the informal caregivers, the integrated programme resulted in a significant reduction in the perceived care burden of the informal caregiver. This may indicate that elements of the integrated programme, such as consultation with the stroke coordinator and stroke education, may support informal caregivers in accomplishing their supporting role. This is in accordance with the results of a review of Visser-Meily and colleagues[32] who concluded that counselling programs which focus on the problems of the informal caregiver, instead of (only) on the problems of the patients, appear to have the most favourable outcomes. In our programme, the problems and experiences of the informal caregiver were explicitly addressed in different modules.

This study is one of few studies that focusses on improving stroke rehabilitation and aftercare for frail older stroke patients and their informal caregivers. However, this study has several limitations. First, we did not reach our inclusion goal of 256 patients, although we took all possible and necessary actions (i.e. extending inclusion period, extending the number of nursing homes) to increase the number of patients. This may have underpowered our multilevel analyses. However, the estimated difference between intervention and usual care group on our primary outcome daily activity (i.e. 1.69) is below the minimal effect that is still considered clinically relevant (i.e.3.5). Therefore, it is unlikely that including the intended number of patients would have resulted in a statistically significant effect on our primary outcome. However, for the psychosocial functioning subscale of the Stroke Specific Quality of life scale (p=.054) accounts that a higher power may have resulted in a statistical significant favourable effect for patients in the intervention group on this subscale.

Second, because we randomised on patient level and not on nursing home level, care professionals treated both people in the intervention group and usual care group. Therefore, it is possible that treatment for persons in the usual care group was contami-

nated with elements of the programme which may have led to an underestimation of the effects of the programme. Although a number of elements of the programme were exclusively available for persons in the intervention group (such as the meetings with the stroke care coordinator, the multidisciplinary outpatient rehabilitation, and the stroke education course), it is still possible that other elements of the intervention were also applied among persons in the usual care group. However, we have tried to reduce this risk of contamination by emphasizing during the training of the care professionals that the programme elements should exclusively be applied in the intervention group. In addition we repeatedly checked whether contamination has occurred during regular visits of the research team to the participating organisations. During these visits care professionals confirmed that the intervention was only applied to persons in the intervention group. Furthermore, after the intervention period, we checked during a group interview with a sample of the participating care professionals whether contamination had occurred, which was not the case according to the care professionals.

Third, patients, caregivers and care professionals could not be blinded for treatment allocation, which might have created some bias. However, in order to reduce the risk of any additional bias, the outcome measurements were performed by research assistants who were blinded for treatment allocation, and the same accounts for the statistical analyses.

Fourth, there could have been interference by possible language disturbances caused by stroke. Although we examined cognition by the MMSE we cannot rule out the fact that possible aphasic syndromes may have caused interference because we did not conduct a specific language assessment for stroke. Despite that, randomisation limited the chance that any possible language disturbance in our population influenced our results.

Fifth, the baseline measurement of the FAI was based on the activity level of patients three months before stroke occurred, as estimated by the patient. It is possible that this resulted in recall bias. However, it is likely that this accounts for patients in both the usual care and intervention group, which makes it unlikely that is has influenced our results.

Conclusion

This study shows that an integrated multidisciplinary rehabilitation programme for frail older patients with stroke and their caregivers had no effect on the activity level of these patients. However, the intervention did show a significant favourable effect on autonomy regarding outdoor activities as perceived by the patients. Furthermore,

we found also a significant favourable effect on the perceived care burden of informal caregivers. Based on these results, the programme might be considered promising in providing adequate aftercare. However, adaptation of the programme is recommended to increase its feasibility and to improve its favourable effects for patients and informal caregivers. More research is needed to increase knowledge and evidence of effective methods to increase daily activity level in (older) patients with stroke.

Abbreviations
Not applicable

Declarations

Ethics approval and consent to participate
Ethical approval was provided by the medical ethics committee of Maastricht University Medical Centre (MUMC+), the Netherlands (ISRCTN62286281, NTR2412). All participants including patients and informal caregivers gave all written informed consent to take part in the study. An overseeing elderly care physician has ruled that all adult patients and informal caregivers have been deemed capable of ethically and medically consenting for their participation in the research presented in this manuscript.

Consent for publication
Not applicable.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Authors' contributions

TV, JvH, JV, and JS were involved in the design of the intervention, the protocol training, acquisitions of subjects, data collection, and data analysis. TV wrote drafts of the manuscript. TV, JvH and FT conducted data analysis. TV, JvH, JV, FT, CvH, and JS were involved in the interpretation of the results. All authors read, critically reviewed and approved the final manuscript.

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References

1. Katan M, Luft A. Global Burden of Stroke. Semin Neurol. 2018 Apr;38(2):208-211.
2. Feigin VL, Norrving B, Mensah GA. Global Burden of Stroke. Circ Res. 2017 Feb 3;120(3):439-448.
3. Actiz, infographic geriatrische revalidatiezorg 2015.
4. Vaartjes I, van Dis I, Visseren FLJ, Bots ML. In: Hart- en vaatziekten in Nederland 2010, cijfers over leefstijl- en risicofactoren, ziekte en sterfte. Vaartjes I, Dis I, Visseren FLJ, Bots ML, editor. Den Haag: Nederlandse Hartstichting; 2010. Incidentie en prevalentie van hart- en vaatziekten in Nederland.
5. Gommer AM, Poos MJJC. Beroerte: prevalentie, incidentie en sterfte naar leeftijd en geslacht. Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM; 2011.

6. Desrosiers J, L Noreau L, Rochette A, Bravo G, Boutin C. Predictors of Handicap Situations Following Post-Stroke Rehabilitation. Disabil Rehabil 2002 Oct 15;24(15):774-85.

7. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: evidence-based clinical practice guidelines. J Rehabil Med. 2006;38(3):153–158.

8. van Almenkerk S, Smalbrugge M, Depla MF, Eefsting JA, Hertogh CM. What predicts a poor outcome in older stroke survivors? A systematic review of the literature. Disabil Rehabil. 2013 Oct;35(21): 1774-82.

9. Heijnen R, Limburg M, Evers S, Beusmans G, van der Weijden T, Schols J. Towards a better integrated stroke care: the development of integrated stroke care in the southern part of the Netherlands during the last 15 years (Special 10th Anniversary Edition paper). Int J Integr Care. 2012 Apr-Jun;12:e123.

10. Bull MJ. Managing the transition from hospital to home. Qualitative Health Res. 1992;2:27–41.

11. Cott CA, Wiles R, Devitt R. Continuity, transition and participation: preparing clients for life in the community post-stroke. Disabil Rehabil. 2007;29(20–21):1566–1574.

12. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database Syst Rev. 2003. p. CD002925.

13. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR. Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care. 2001;39(11):1217–1223.

14. Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF. Therapy-based rehabilitation services for patients living at home more than one year after stroke. Cochrane Database Syst Rev. 2008;16(2):CD005952.

15. Vluggen TP, van Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012 Dec 31;12:164.

16. Rockwood K, Stolee P, Fox R: Use of goal attainment scaling in measuring clinically important change in the frail elderly. J Clin Epidemiol 1993,46(10):1113–1118.

17. Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? Disabil Rehabil. 2006;28(13–14):841–847.

18. Folstein MF, Folstein SE, McHugh PR. Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975;12(3):189–198.

19. Burton L, Tyson SF. Screening for cognitive impairment after stroke: A systematic review of psychometric properties and clinical utility. J Rehabil Med. 2015 Mar;47(3):193-203

20. Ojagbemi A, Owolabi M, Bello T, Baiyewu O. Stroke severity predicts poststroke delirium and its association with dementia: Longitudinal observation from a low income setting. J Neurol Sci. 2017 Apr 15;375:376-381.

21. Schuling J, de Haan R, Limburg M, Groenier KH. The Frenchay Activities Index. Assessment of functional status in stroke patients. Stroke. 1993;24(8):1173–1177.

22. Weinberger M, Samsa GP, Schmader K, Greenberg SM, Carr DB, Wildman DS. Comparing proxy and patients' perceptions of patients' functional status: results from an outpatient geriatric clinic. J Am Geriatr Soc. 1992;40(6):585–588.

23. Williams LS, Weinberger M, Harris LE, Biller J. Measuring quality of life in a way that is meaningful to stroke patients. Neurology. 1999;53(8):1839–1843.

24. Cardol M, de Haan RJ, van den Bos GA, de Jong BA, de Groot IJ. The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA) Clin Rehabil. 1999;13(5):411–419.

25. Brouwer WB, NJ v E, van GB, Redekop WK. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res. 2006;15(6):1005–1021.

26. van den Berg B, Spauwen P. Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. Health Econ. 2006;15(5):447–460.

27. Vluggen T, van Haastregt J, Verbunt J, van Heugten C, Schols J. Feasibility of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients: a process evaluation. BMC Neurology. 2020;20:219.

28. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008;337:a1655.

29. Fens M, Vluggen T, van Haastregt JC, Verbunt JA, Beusmans GH, van Heugten CM. Multidisciplinary care for stroke patients living in the community: a systematic review. J Rehabil Med. 2013 Apr;45(4):321-30.

30. de Graaf JA, van Mierlo ML, Post MW, Achterberg WP, Kappelle LJ, Visser-Meily JM. Long-term restrictions in participation in stroke survivors under and over 70 years of age. Disabil Rehabil. 2017 Jan 5:1-9.

31. Graven C, Brock K, Hill KD, Cotton S, Joubert L. First Year After Stroke: An Integrated Approach Focusing on Participation Goals Aiming to Reduce Depressive Symptoms. Stroke. 2016 Nov;47(11):2820-2827.

32. Visser-Meily A, van Heugten C, Post M, Schepers V, Lindeman E. Intervention studies for caregivers of stroke survivors: a critical review. Patient Educ Couns 2005; 56: 257–67.

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CHAPTER 6

Feasibility of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients: a process evaluation

Background
Almost half of the stroke patients admitted to geriatric rehabilitation has persisting problems after discharge. Currently, there is no evidence based geriatric rehabilitation programme available for older stroke patients, combining inpatient rehabilitation with adequate aftercare aimed at reducing the impact of persisting problems after discharge from a geriatric rehabilitation unit. Therefore, we developed an integrated multidisciplinary rehabilitation programme consisting of inpatient neurorehabilitation treatment using goal attainment scaling, home based self-management training, and group based stroke education for patients and informal caregivers. We performed a process evaluation to assess to what extent this programme was performed according to protocol. Furthermore, we assessed the participation of the patients in the programme, and the opinion of patients, informal caregivers and care professionals on the programme.

Methods
In this multimethod study, process data were collected by means of interviews, questionnaires, and registration forms among 97 older stroke patients, 89 informal caregivers, and 103 care professionals involved in the programme.

Results
A part of patients and informal caregivers did not receive all key elements of the programme. Almost all patients formulated rehabilitation goals, but among two thirds of the patients the goal attainment scaling method was used. Furthermore, the self-management training was considered rather complex and difficult to apply for frail elderly persons with stroke, and the percentage of therapy sessions performed in the patients' home environment was lower than planned. In addition, about a quarter of the patients and informal caregivers attended the education sessions. However, a majority of patients, informal caregivers and care professionals indicated the beneficial aspects of the programme.

Conclusion
This study revealed that although the programme in general is perceived to be beneficial by patients, and informal and formal caregivers, the feasibility of the programme needs further attention. Because of persisting cognitive deficits and specific care needs in our frail and multimorbid target population, some widely used methods such as goal attainment scaling, and self-management training seemed not feasible in their current form. To optimize feasibility of the programme, it is recommended to tailor these elements more optimally to the population of frail older patients.

Keywords: Stroke, Geriatric rehabilitation, Elderly persons, Process evaluation

Abstract

Background

The population of older stroke patients with persisting physical and psychosocial problems is rapidly increasing due to ageing of the population[1-4]. The prevalence of stroke among Dutch people of 65 years or older is estimated at 71 per 1,000 males and 56 per 1,000 females[5]. Almost half of the stroke patients admitted to geriatric rehabilitation has persisting problems after discharge such as paralysis, cognitive deficits, fatigue, behaviour problems and depression[6-12]. These problems might result in a decrease of the patient's functional level, increased social isolation and can eventually result in admission to a long-term care facility. Furthermore, these problems may have a negative impact on the care burden and quality of life of their informal caregivers[13,14]. This emphasizes the importance of continuity of care after home discharge of older stroke patients by providing adequate aftercare to prevent these problems.

In current stroke rehabilitation there is only limited attention for specialized aftercare to tackle and prevent further negative impact on patients and informal caregivers[15-17]. This indicates that it is important to improve stroke rehabilitation in providing more specialized aftercare which includes effective methods to increase the long term effects of stroke rehabilitation, and prevent or postpone admission to long term care facilities. However, there is no evidence based geriatric rehabilitation programme available for older stroke patients combining inpatient rehabilitation with adequate aftercare aimed at reducing the impact of persisting problems after discharge from a geriatric rehabilitation unit[18-31].

Therefore, we developed a multidisciplinary rehabilitation programme in which inpatient rehabilitation and after care are integrated. The new integrated programme is based on a combination of evidence available from stroke research about inpatient rehabilitation and aftercare, and expert knowledge from daily practice [17,32]. The programme focusses on increasing the older stroke patient's level of daily activity, functional independence, perceived quality of life, and social participation[32]. In addition, the programme aims to reduce the perceived burden of care and to increase the quality of life of the informal caregivers[32].

The effects of this newly developed rehabilitation programme have been evaluated by means of a multicentre randomized controlled trial with an intervention group receiving the new programme and a control group receiving usual care and will be reported elsewhere. The programme showed favourable effects on participation and autonomy of patients and on the care burden of informal caregivers.

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Alongside this randomized controlled trial, we conducted a process evaluation to assess the feasibility of the program, based on the framework for process evaluation described by Saunders et al.[33]. The current paper presents the results of this process evaluation of which the aims were: 1) to evaluate to what extent the integrated multidisciplinary rehabilitation programme was performed according to protocol (fidelity, dose delivered); 2) to evaluate the participation of the patients in the programme (reach and dose received exposure); and 3) to assess the opinion of patients, informal caregivers and care professionals on the programme (dose received satisfaction and context)[33]. More insight into these factors is relevant for both researchers and care professionals, because knowledge about the care processes could help to identify ways to optimize stroke rehabilitation for older persons and to set the agenda for future research[33,34].

Methods

Design
This process evaluation study followed a multimethod design including qualitative and quantitative research methods (see table 2). Process data were collected during a period of 12 months after patients were included in the rehabilitation programme. The study was conducted in the period of November 2010 and December 2015 with a total study period of 60 months. This process evaluation was conducted alongside a randomized controlled trial to evaluate the effectiveness of the newly developed multidisciplinary geriatric rehabilitation programme[32]. The randomized trial is registered by the following trial registration: International Standard Randomized Controlled Trial Register Number (ISRCTN62286281), and The Dutch Trial Register (NTR2412). This study is funded with a grant (grant number:313070301) from the Netherlands Organisation for Health Research and Development (ZonMw) as part of the National Care for the Elderly Programme.

Integrated multidisciplinary rehabilitation programme
The programme, which was evaluated alongside the randomized controlled trial, consists of three care modules: 1) inpatient neurorehabilitation treatment; combined with 2 modules after discharge: 2) home based self-management training for patient and informal caregiver; and 3) stroke education for patient and informal caregiver. The intervention programme was delivered in eight geriatric rehabilitation units in the Netherlands. The programme was developed in close collaboration with members of the multidisciplinary stroke teams of the eight care organisations involved. Much effort was put in the implementation of the programme by training the care professionals in the study protocol, by periodical visits of the participating locations, and in being standby for tackling questions by the researchers of the study. The group of selected

Table 1: Content differences between integrated multidisciplinary rehabilitation programme and usual care

	Integrated multidisciplinary programme	Usual care
Care content		
Multidisciplinary stroke team	+	+
Care based on Dutch stroke guidelines	+	+
Tailored approach with Goal Attainment Scaling	+	-
Self-management	+	-
Stroke education	+	-
Home therapy during nursing home admission	+	-
Multidisciplinary outpatient rehabilitation	+	-
Home visits of stroke care coordinator	+	-
Care organisation		
Stroke care coordinator	+	-
Multidisciplinary team meetings in nursing home	+	+
Multidisciplinary team meetings after discharge	+	-
Electronic patient record	+	-

care professionals consisted of physical therapists, occupational therapists, speech therapists, psychologists, elderly care physicians, and stroke care coordinators. The main differences between the integrated multidisciplinary rehabilitation programme and usual care are presented in table 1 and described in more detail below.

Stroke care coordinator

In order to improve continuity of care, a stroke care coordinator was introduced as a member of the rehabilitation team. The stroke coordinator provides support to the patient and informal caregiver, facilitates the transition between rehabilitation and returning home and supports the collaboration between the care professionals involved.

Module 1: inpatient neurorehabilitation treatment

The first module starts when the patient is admitted to the geriatric rehabilitation unit and focuses on (re)learning the abilities needed to function as independently as possible in the home environment after discharge. At the start of this module, an individual treatment plan is developed with the patient. This treatment plan includes personal rehabilitation goals used during inpatient rehabilitation care and aftercare at the patient's home. The method to formulate rehabilitation goals with the patient was a simplified version of the Goal Attainment Scaling (GAS) method[35, 36]. GAS has shown to be an appropriate method in rehabilitation treatment among elderly people[35, 36]. When

the patient is admitted to the geriatric rehabilitation unit, the coordinator organizes an introductory meeting with the patient and primary informal caregiver. In this meeting, the coordinator provides general information about the rehabilitation programme. During their stay in the geriatric rehabilitation unit, the patient and an occupational therapist or physical therapist (depending on the individual care needs of the patients), visit the home of the patient to train with the patient in their own home environment. The therapist and patient use the home training sessions to train specific goals to increase and empower functional independence of the patient after discharge.

During one of the visits the therapists also check whether the patient's home needs adjustments before discharge[37-39]. Additional financial means were arranged via the research project to facilitate the stroke team in organizing and performing these home therapy sessions (because travel expenses for therapist were not reimbursed in the regular reimbursement system). The care within this module is conducted by a multidisciplinary stroke team consisting of care professionals working at the geriatric rehabilitation unit including an a physical therapist, an occupational therapist, a speech therapist, a psychologist, an elderly care physician, and a stroke care coordinator.

To evaluate the treatment progress, multidisciplinary team meetings are organized every four weeks during the intervention period. To facilitate optimal communication and information transfer between care professionals, an electronic patient record is available for the primary and secondary care professionals involved in the programme. Furthermore, during the rehabilitation process the coordinator facilitates the transition of the patient from in-patient geriatric rehabilitation care to home-based (after)care by supporting the collaboration between the multidisciplinary stroke team of the geriatric rehabilitation unit, community health services and general practitioner. This module has a maximum duration of 2 months depending on the rehabilitation goals and care needs of the patient and informal caregiver.

Module 2: home based self-management training for patient and informal caregiver
The second module starts after discharge of the patient to the home environment and is focused on learning to cope with persisting cognitive and functional impairments as a result of stroke. To optimize the patient's functional level and participation at least 50% of this module (i.e. therapy sessions with physical and/or occupational therapist) should be provided ambulatory in the home environment of the patient. The remaining part can be provided in an outpatient clinic. Furthermore, after discharge, the stroke coordinator conducts at least two home visits to the patient to support both patient and informal caregiver to improve their coping strategies. This training is based on strategies to enhance chronic disease self-management[40-42]. Furthermore, the stroke coordinator organizes multidisciplinary stroke team meetings with the primary care professionals involved. These meetings are aimed at evaluating the treatment process and to set

rehabilitation goals for further treatment. The care in this module is provided by the same professionals of the multidisciplinary team of care professionals of the geriatric rehabilitation unit participating in module 1 and complemented with new care professionals from primary care. All care and support provided in this module is coordinated by the stroke coordinator under supervision of the general practitioner. This module has a maximum duration of 4 months, depending on the care needs of both patient and informal caregiver.

Module 3: stroke education for patient and informal caregiver
The third module is a stroke education module for patients and their informal caregivers. This module consists of four group sessions of two hours (two mixed sessions with patients and informal caregivers and two sessions with patients and informal caregivers in separate groups) focusing on the psychological and emotional consequences of stroke, perceived problems in independent living and participation in society, and the role of the informal caregiver. The patients and informal caregivers are invited by the stroke care coordinator to participate in the course. The participation of the patient in the course should be planned within the intervention period of six months, and after patients were discharged home. The course is given by a (neuro) psychologist and two volunteers of the Dutch Stroke Patient Association and Informal Caregivers Association and a social worker.

Training care professionals
All care professionals of the participating stroke teams were trained in conducting the programme according to protocol. The training was conducted by members of the research team (TV, JvH and JV) during a four hours session. The training consisted of interactive sessions about the key elements of the intervention, including the use of Goal Attainment Scaling (GAS), the training at the patients' home, the use of self-management principles and the use of the electronic patient record. Care professionals who were not able to attend the training sessions received an individual session about the use of the protocol.

Study population
The research population of the process evaluation consisted of three groups. The first group were 97 older stroke patients, who were allocated to the rehabilitation programme[32]. Patients were selected for participation in the present study when they met the following inclusion criteria: admission to one of the eight participating geriatric rehabilitation units located in the south of the Netherlands, due to a recent stroke, aged 65 or over, living independently in the community before the stroke, expected to be able to return home after discharge (as judged by the multidisciplinary stroke team),

and giving informed consent to participate[32]. If the patient was unable to give informed consent, or the patient was medically unstable or had cognitive deficits and was not able to start rehabilitation on the basis of clinical judgment, the patient was excluded.

The second group consisted of 89 informal caregivers of the patients allocated to the rehabilitation programme. A person was considered to be the primary informal caregiver when the patient indicated him/her as the person from his social network who provides help with his or her activities of daily living, or instrumental activities of daily living on a long-term base. Informal caregivers could be included when they gave informed consent to participate in the study.

The third group consisted of 103 care professionals who participated in the eight stroke teams who conducted the rehabilitation programme. All participating care professionals were experienced in stroke rehabilitation and all care professionals who were involved in the treatment of patients in the intervention group were trained by a 3 hour training in all key elements of the new rehabilitation programme. The stroke teams consisted of care professionals working at the participating geriatric rehabilitation units and community health care services, including elderly care physicians (N=11), physical therapists (N=24), occupational therapists (N=18), speech therapists (N=20), dieticians (N=10), (neuro)psychologists (N=7), and stroke care coordinators (N=13).

Measurement instruments

Patients and informal caregivers
The feasibility of the rehabilitation programme was assessed during a period of 12 months after the start of the programme for the individual patients (see table 2). Process data from the patients were gathered by a trained research assistant by means of structured face-to-face interviews at 6 and 12 months, and after completion of module 3. Process data from the informal caregivers was gathered by a self-administered questionnaire at 6 and 12 months, and after completion of module 3. The data of module 3 was gathered on different time points because starting the module was dependent on the possibility to start module 3 with enough participants. On request of the informal caregiver, a research assistant could assist the informal caregiver in filling out the questionnaire.

Care professionals
Quantitative data concerning the implementation of the programme were gathered at the end of the randomized controlled trial by means of registration forms during the intervention period. The forms were included in the electronic patient records and were filled out by the care professionals who conducted the programme. In addition, a struc-

Table 2: outcome measures and measurement instruments of the process evaluation

Process outcomes	Patient	Informal caregiver	Care professionals		
	SI	SAQ	RF	SSQ	GI
1. Performance of the programme according to protocol and participation in the programme					
Module 1: inpatient neurorehabilitation treatment for patients (2 months)					
Development of rehabilitation goals			X	X	X
The use of the simplified goal attainment scaling method to set rehabilitation goals			X	X	X
Introduction meeting of stroke care coordinator			X	X	X
At least one home visit by 1) physical therapist and/or 2) occupational therapist to check for home adjustments			X	X	X
At least two therapy sessions in the patient's home			X	X	X
Module 2: home based self-management training for patient and informal caregiver (4 months)					
Practicing self-management skills			X	X	X
Involving informal caregiver in self-management training			X	X	X
At least two home visits to the patient by the stroke care coordinator			X	X	X
At least 50% of the treatment sessions by 1) physical therapist and/or 2) occupational therapist at home			X		X
Number of patients and informal caregivers participating in the intervention group *(module 1 & 2)*			X		X
Module 3: stroke education for patient and informal caregiver					
Number of education sessions performed			X		X
Number of patients and informal caregivers attending the education sessions *(module 3)*			X		X
2. Opinion of patients, informal caregivers and Care professionals on the programme					
Patients' and informal caregivers					
Module 1: inpatient neurorehabilitation treatment for patients (2 months)					
Perceived benefit of 1) setting rehabilitation goals, 2) therapy sessions in the patients' home, 3) guidance of the stroke care coordinator	X	X			

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Table 2: outcome measures and measurement instruments of the process evaluation *(continued)*

Process outcomes	Patient	Informal caregiver	Care professionals		
	SI	SAQ	RF	SSQ	GI
Module 2: home based self-management training for patient and informal caregiver (4 months)					
Perceived benefit of 1) therapy sessions in the patients' home, 2) home visits of the stroke care coordinator, 3) training self-management skills, 4) developing action plans to fulfil self-management training	X	X			
Module 3: stroke education for patient and informal caregiver					
Perceived benefit of the four education sessions	X	X			
Care professionals					
Opinion multidisciplinary team					
Benefit of 1) home visit to check whether home adjustments are needed *(module 1)*, 2) the development of rehabilitation goals, 3) use of goal attainment scaling method *(module 1 & 2)*, 4) therapy sessions in the patients' home *(module 2)*				X	X
Opinion stroke care coordinator					
Benefit of 1) development of rehabilitation goals *(module 2)*, 2) use of goal attainment scaling method *(module 2)*, 3) use of a workbook *(module 2)*, 4) practising self-management skills, 5) home visits after discharge *(module 2)*, 5) personal guidance of the stroke care coordinator *(module 1 & 2)*, 6) four education sessions *(module 3)*.				X	X

SI = structured interview; SAQ = self-administered questionnaire; RF = research form; SSQ = semi-structured questionnaire; GI = group interview

tured questionnaire (containing questions about the benefit of the key elements of the programme and opinion on the program) was sent after completion of the trial to all 103 care professionals who were involved in conducting the rehabilitation programme. The structured questionnaire had two versions; a version for the stroke care coordinators (N=13) and a version for the stroke care team members (N=90) (see table 2 for further details on the contents of the questionnaire).

Furthermore, an additional group interview session with a small selection, of the 103 care professionals, with all involved care professionals of the stroke team represented, was scheduled within 3 months after data from the structured questionnaires were collected. Results from the questionnaires were used to select topics for the group inter-view. For the selection of care professionals for the interview the participating geriatric rehabilitation units were divided into two groups based on the number of participants in the programme during the study period of 48 months. One group consisted of the four geriatric rehabilitation units that included more than 30 patients in the rehabilita-tion programme. The second group consisted of the four geriatric rehabilitation units that included 30 patients or less in the rehabilitation programme. In both groups 10 care professionals working in community services and on a geriatric rehabilitation unit were selected by a purposive sampling method and invited to participate in the group interview. They were selected based on their experience with the programme. Both the invited groups consisted of stroke care coordinators (N=3), an elderly care physician (N=1), physical therapists (N=2), an occupational therapist (N=1), a speech therapist (N=1), and neuropsychologists (N=2). Both interviews had a planned duration of 1.5 hours and were conducted by two researchers (TV and JvH). Both complete group interviews were audio recorded; a summary of the interviews was made by TV and JvH on the basis of the recording. The summaries were sent to the participating care profes-sionals for confirmation (member check).

Data Analysis

Quantitative data from the structured interviews, self-administered questionnaires and registration forms were analysed by means of descriptive statistics using SPSS software package version 23[32].

Qualitative data from the structured interviews, self-administered questionnaires, and group interview were classified into categories based on the given answers.

Ethical considerations

The process evaluation was approved by the medical ethics committee of the Uni-versity Hospital Maastricht and Maastricht University (MUMC+), the Netherlands. The alongside conducted randomized controlled trial is registered by the following registra-

tion numbers; International Standard Randomized Controlled Trial Register Number (ISRCTN62286281), and The Dutch Trial Register (NTR2412). Informed consent was obtained from all participating patients and informal caregivers.

Results

Response and background characteristics

Eighty four out of 97 patients (87%) participated in the interview after 6 months, and 70 patients (72%) participated in the interview after 12 months. Participating patients had a mean age of 78.8 years (SD=6.3), an a mean activity level (FAI score) of 40.2 (SD=8.8) a mean functional independence level (Katz-15 score) of: 6.0 (SD=4.0), and mean cognitive score (MMSE-score: 21.9, SD=5.2, threshold: ≤23.0). Regarding the informal caregivers, 68 informal caregivers out of 89 (76%) completed the questionnaire after 6 months, and 64 informal caregivers (71%) after 12 months. Participating informal caregivers had a mean age of 61.0 years (SD=13.5), and a mean self-rated burden vas of 4.0 (SD=2.4). Main overall reasons why patients and informal caregivers did not participate in the interviews were loss of interest (N=6), lack of time (N=3), an intercurrent illness (N=4), or deceased (N=7). Background characteristics of patients and informal caregivers are presented in table 3.

A total of 59 care professionals (57%) responded to the questionnaire. The group care professionals, who responded, consisted of elderly care physicians (N=2, 3%), physical therapists (N=16, 27%), occupational therapists (N=10, 17%), speech therapists (N=12, 20%), neuropsychologists (N=3, 5%), dieticians (N=3, 5%), and stroke care coordinators (N=13, 22%). The group interview was conducted with ten health professionals. All ten

Table 3: Background characteristics of included patients and informal caregivers

	Patients (N=97)	Informal caregivers (N=89)
Characteristics	*N (%)*	*N (%)*
Mean (SD) age	79 (7)*	61 (14)*
N (%) Female	69 (71)	53 (59)
Relationship with the patient		
- N (%) Spouse/partner	n.a.	28 (31)
- N (%) Family	n.a	59 (66)
- N (%) Friend	n.a.	2 (2)
- N (%) Other	n.a.	1 (1)
- N (%) No informal caregiver	n.a.	7 (7)

n.a.= not applicable; *=(SD)

care professionals that were invited participated in the interview. The presented results of the interview were based on consensus of opinion within the group of care professionals who participated in the interview.

All care professionals who conducted the programme were experienced in stroke rehabilitation of elderly persons and were educated and trained in the relevant aspects of the intervention protocol.

Performance according to protocol and participation in the programme

Module 1: inpatient neurorehabilitation treatment for patients
At baseline 97 patients were allocated to the intervention group and started with module 1 in the geriatric rehabilitation unit. After 6 months 11 patients had dropped out of the rehabilitation programme because of cognitive deficits (N=3), loss of interest (N=3), being deceased (N=3) or other reasons (N=2). The first module was conducted from 16 November 2010 until 4 December 2014.
In table 4 the key components of the programme are presented. The multidisciplinary team developed with 94 (97%) of the 97 patient's individual rehabilitation goals during inpatient and home based rehabilitation. During rehabilitation about two thirds (N=60, 62%) of the patients developed rehabilitation goals with a care professional by using the goal attainment scaling (GAS) method.
During the group interview there was consensus between the care professionals that setting rehabilitation goals by using the GAS method at the start of the rehabilitation was often difficult. Most participating care professionals mentioned that difficulties were often caused by limitations in communication skills of the patient and lack of insight in their disease. In those cases the therapist often set goals with the patient without using the GAS method. Almost all patients (N=96, 99%) received an introduction meeting with the stroke care coordinator.
About half of the patients (N=50, 52%) received at least one of the two home visits conducted by an occupational or physical therapist to practice in their own home environment and to check whether home adaptations should be made; eleven percent (N=11) of the patients received both therapy sessions at the patient's home.
The group interview revealed that there was consensus between the therapists about the usefulness of home therapy, but it was often not performed because it was too time consuming due to travel distance.
Within the intervention period of two months 46 of the 97 patients (48%) were discharged home from the geriatric rehabilitation unit. However, almost half of the group (N=51, 52%) was still not discharged because of complications that delayed the rehabilitation such as stroke recidivism, cardiac complication and delay in home adaptations or

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waiting for alternative accommodation. These patients continued module 1 awaiting to be discharged back home. The mean duration of stay in the rehabilitation unit was 83 days (range 7-456 days).

Module 2: home based self-management training for patient and informal caregiver
After discharge from the geriatric rehabilitation unit, all 86 patients who were still participating in the study continued the programme with module 2. Of the total group of patients (N=86, 89%) who started module 2, 74 patients (86%) had an informal caregiver. The second module was conducted between 13 December 2010 and 14 December 2014. Eighty-four patients of the total group of patients (N=97) (87%) practiced self-management skills, of which 53 patients (55%) practiced self-management skills without their informal caregiver. These practice sessions were conducted at the patient's home under guidance and supervision of the stroke care coordinator. During the interview with care professionals and the stroke care coordinators there was consensus about that training self-management skills was often too difficult for patients because it was complicated for them to develop and carry out action plans by themselves. In a lot of cases the therapists or stroke care coordinators had to set relevant and realistic goals with the patients because the patient was not capable of setting them by themselves.
In the intervention protocol it was planned that patients should receive a minimum of one home visit of the stroke coordinator to check how the patient and informal caregiver were doing at home. A total of 78 patients (80%) received at least one home visit and 60 patients (62%) received two or more home visits at the patient's home. The number of home visits by the stroke care coordinator ranged between 1 and 5 visits, with a mean of 1.7 visits per patient.
For 39% of the patients (N=38) at least half of the treatment sessions by the physical therapist was given at the patient's home. In case of occupational therapy only 27% of the patients (N=26) received therapy at home. The other treatment sessions were given in day treatment, practice or outpatient care setting. Most important reason why therapy was not conducted at home was that home therapy was considered very time consuming and costly.
All participating eight geriatric rehabilitation units organized a multidisciplinary meeting every four weeks for care professionals who were involved in the rehabilitation of the patients who were allocated to the intervention group. Five out of eight participating geriatric rehabilitation units used the for the intervention developed electronic patient record for communication between the care professionals. The reason for not using the electronic patient record was that these three organisations used another electronic patient record, which was not compatible with the study electronic programme. All patients completed this module within 4 months.

Table 4: Performance according to protocol

Performance according to protocol[*]	N (%)
Module 1: inpatient neurorehabilitation treatment for patients (2 months)	
Number of patients started with the module	97 (100)
Number of informal caregivers started with the module	89 (100)
Development of rehabilitation goals with patient	94 (97)
The use of the goal attainment scaling method to set rehabilitation goals	60 (62)
Introduction meeting of stroke care coordinator with patient	96 (99)
At least one home visit by the physical therapist or occupational therapist to check for home adjustments	50 (52)
At least two therapy sessions by the physical therapist of occupational therapist in the patient's home	11 (11)
Module 2: home based self-management training for patient and informal caregiver (4 months)	
Number of patients started with the module	86 (89)
Number of informal caregivers started with the module	74 (76)
Practicing self-management skills with the patient	53 (55)
Involving informal caregiver in self-management training of the patient	31 (32)
At least two home visits to the patient by the stroke care coordinator	60 (62)
At least 50% of the treatment sessions by physical therapist at home	38 (39)
At least 50% of the treatment sessions by occupational therapist at home	26 (27)
Module 3: stroke education for patient and informal caregiver	
Patients	
Number of patients participated	24 (25)
Mean number of sessions participated (out of a total of 4 sessions)	3.1
Informal caregivers	
Number of informal caregivers participated	23 (26)
Mean number of sessions participated (out of a total of 4 sessions)	3.1

*97 patients and 89 informal caregivers participated; [a] education sessions performed (%); [b] total amount of patients / total amount of informal caregivers participated in the intervention group.

Module 3: stroke education for patient and informal caregiver

The patients who completed module 1 and 2 and thereafter still were in the study (N=86) were invited for the four sessions of module 3. The information was handed out with further instruction and clarification by the stroke coordinator during a home visit with the individual patient and informal caregiver. Of the 86 patients who were invited to module 3, 68 (70%) agreed to participate and eventually 24 (25%) participated. The 24 patients who agreed to participate had a mean participation of 3.1 sessions. In total 64 of the 89 (72%) informal caregivers were invited, 23 (26%) informal caregivers partici-pated with an average of 3.1 sessions. Main reason why patients (and related caregivers) not attended the sessions was because they were not interested in the sessions (N=39), illness (N=11), difficulties with transportation (N=8), readmission to a geriatric rehabili-

tation unit (N=5), too stressful (N=4), on vacation (N=3), work informal caregiver (N=2), deceased (N=2), and unknown (N=11). Thirteen education sessions had to be cancelled because there were too few participants.

We planned four sessions per participating rehabilitation unit per every 6 months. Every cycle a group of twelve persons at the most (6 patients and 6 informal caregivers) was included. Taken the inclusion period and the amount of participating rehabilitation units (N=8) into account we should have performed 15 education programmes of 4 sessions each, but eventually we only performed 6 education programmes of 4 sessions (40%) sessions. Main reason of the low number of sessions performed was the relatively low number of included participants per setting, which made it difficult to form groups and a lack of interest among the potential participants. Furthermore, the traveling distance to the sessions was in some cases a reason for not attending.

Opinions on the programme

Patients

All patients who participated in the programme were asked to give their opinion on the key components of the programme they had received. The opinion of the patients on the different elements of the programme is presented in table 5.

Of the fifty-six patients who followed module 1 and formulated goals with the care professionals, 54 patients (96%) indicated that they benefited from it. Almost all patients (98%) of the patients (N=51) who actually did receive home therapy reported to have benefited from these therapy sessions. From the patients who received module 2 and trained self-management skills by setting goals also almost all patients (N=34, 97%) indicated that they had benefited from this key element of the programme.

Patients who participated in the rehabilitation programme were asked how the programme could be improved. They indicated that the programme could be improved by providing more information about the program itself to the participants, increasing the support patients receive from the stroke coordinator and providing more information to the patients about the roles of the different care professionals who perform the programme.

Informal caregivers

Of the informal caregivers of which the patient actually followed module 1, 93% (N=50) perceived benefit of the support of the stroke care coordinator. Eighty-seven percent of the informal caregivers (N=40) of which the patient followed module 2 perceived benefit

Table 5: Patients and informal caregivers' perceived benefit of the programme*

Key components of the programme	N (%) patients who reported to have benefited from component	N (%) informal caregivers who reported to have benefited from component
Module 1: inpatient neurorehabilitation treatment for patients (2 months)		
Setting rehabilitation goals with the Care professionals *(response patients N=56)*	54 (96)	- -
Therapy sessions in the patients' home *(response patients N=52)*	51 (98)	- -
Guidance of the stroke care coordinator *(response patients N=55 / informal caregivers N= 54)*	52 (95)	50 (93)
Module 2: home based self-management training for patient and informal caregiver (4 months)		
Home therapy sessions by a therapist *(response patients N=46)*	43 (93)	- -
Home visits of the stroke care coordinator *(response patients N=52/ informal caregivers N=50)*	47 (90)	43 (86)
Setting goals for training self-management skills *(response patients N=35 / informal caregivers N=46)*	34 (97)	40 (87)
Developing action plans to fulfil self-management training *(response patient N= 32 / informal caregivers N=42)*	30 (94)	38 (90)
Module 3: stroke education for patient and informal caregiver		
Four education sessions (module 3) *(response patients N=24 / informal caregivers N=28)*	22 (92)	27 (96)

*Measured in patients and informal caregivers who actually did received the key elements of the programme

of goal setting for training self-management skills and 90% of the informal caregivers (N=38) benefited from developing action plans to fulfil self-management training.

The informal caregivers were asked how the programme could be improved. They made the following suggestions: more focus on the necessary home adaptions to facilitate a fast transfer back home, more personal support from the care coordinator during admission, better and faster continuation of the programme after discharge home.

Care professionals

The opinion of the 34 care professionals and 13 stroke coordinators who responded and filled in the questionnaire is presented in table 6. Thirty-three (97%) of the 34 care professionals who conducted all modules of the programme indicated that patients did benefit from the development of rehabilitation goals and 30 care professionals (91%) considered the use of the goals attainment scaling method to be beneficial for patients and informal caregivers. However, the self-management method which was used to stimulate patients in their problem-solving skills was perceived rather complex and

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Table 6: Care professionals' opinion about the benefit of the programme for patients and informal caregivers*

Key components of the programme	N (%) Care professionals who reported that component is beneficial for patient and/or informal caregivers
Opinion multidisciplinary team (without stroke coordinator) (response N=48)	
Development of rehabilitation goals with the patient *(module 1 & 2) (response N=36)*	33 (97)
Use of goal attainment scaling method to develop rehabilitation goals *(module 1 & 2) (response N=33)*	30 (91)
Home visit to check whether home adjustments are needed *(module 1) (response N=19)*	14 (74)
Therapy sessions in the patients' home *(module 2) (response N=23)*	20 (95)
Opinion stroke care coordinator (response N=13)	
Development of rehabilitation goals with the patient (module 2)	12 (92)
Use of goal attainment scaling method to develop rehabilitation goals (module 2)	11 (85)
Use of a workbook to develop rehabilitation goals and action plans (module 2)	9 (69)
Practicing self-management skills with the patient and informal caregiver *(module 2)*	9 (69)
Home visits after discharge *(module 2)*	12 (92)
Personal guidance of the stroke care coordinator *(module 1 & 2)*	12 (92)
Four education sessions *(module 3)*	9 (69)

*Measured among members of the multidisciplinary team and stroke coordinators who conducted the key elements of the programme

difficult to apply. They considered it important to make this method more accessible for this frail population to improve its feasibility.

The stroke care coordinators were unanimously in their opinion about the benefits of developing rehabilitation goals, home visits after discharge and their personal guidance at home.

The results of the group interviews indicated that the education sessions should be changed on a few points. The group suggested to start with the sessions when patients are still at the geriatric rehabilitation unit, and combine the sessions with a training activity such as for example exercising with a physical therapist. Furthermore, in their opinion the group should not include more than maximum 10 patients. A larger group could lead to less interaction between the group members and information loss.

Both care professionals and stroke care coordinators mentioned that multidisciplinary team meetings and using an electronic patient record are important tools to optimize communication during rehabilitation. Finally, recommendations were made to continue the programme without the element of home visits to check for home adaptations and train with the patient at home, because of the time consumption and financial limitations. The role of the stroke care coordinator was indicated as very important and should be continued according to the care professionals. Facilitating further aftercare and guiding stroke patients and informal caregivers after discharge could be very important to prevent decline in functioning of the patient and admission in a long term care facility.

Discussion

This study evaluated the feasibility of an integrated multidisciplinary stroke rehabilitation program, for older persons (65+) who suffered a stroke. The study revealed that the program was conducted only partly according to protocol. A substantial part of patients and informal caregivers did not receive all key elements of the three care modules of the program. Almost all patients formulated rehabilitation goals and received an introduction meeting of the stroke care coordinator, but not for all patients the goal attainment scaling method was used to set these rehabilitation goals. Although goal attainment scaling is the recommended method for setting rehabilitation goals in stroke, its feasibility for this frail older population of stroke patients is limited according to the care professionals. Our results showed that most difficulties were caused by limitations in communication skills of the patient and lack of insight in their disease. Furthermore, the self-management method used to stimulate patients in their problem-solving skills was considered rather complex and difficult to apply for frail elderly persons with stroke, by the care professionals. This could be due to different reasons. First, the capabilities of these frail older persons to process new information are often more limited than in younger stroke patients. Second, it could be that our training of the participating care professionals in learning to teach self-management principles during a training of four hours might have been too short. To increase the application of self-management by care professionals in stroke care it might be necessary to give more intensive training during a longer period of time. Furthermore, self-management strategies were introduced relatively early after stroke. Moulaert et al, also experienced in a study among patients who survived cardiac arrest, that self-management strategies were difficult to implement as an early intervention in the first weeks of rehabilitation[43]. Maybe using this method in the chronic phase of stroke could lead to more effective use. Furthermore, it was observed that although additional financial means were made available for home visits, the amount of home visits to check for necessary adaptations and the conduct of

therapy sessions in the patients' own home environment was lower than planned. Thus, enhancing financial possibilities seems not to be enough in lowering the barrier for therapists to conduct home visits. Main barriers brought up during our group interview with the stroke professionals were time and travel problems. Although, home therapy is valued for its effect to enhance the functional activity and participation level of stroke patients after discharge[44], results of our study indicate that there is still a time and/or travel problem for care professionals which makes it is still rather difficult, in current practice, to organize home therapy.

To tackle time and travel difficulties, telemonitoring could be a feasible and effective alternative to improve recovery, and maintaining the benefits reached during inpatient rehabilitation[45-47].

Finally, we also observed that the attendance of the education module by the patients and informal caregivers was rather low. It seemed to be difficult to motivate older stroke patients and their informal caregivers to visit education sessions about stroke after discharge, and it remains unclear how to improve the feasibility of this module. The majority of the people who declined to participate in this module indicated they were not interested in participation. However, there might be some underlying reasons for this lack of interest which we concluded from our study, such as perceived burden and practical and financial concerns related to travelling to the location. Therefore, providing this module in a more accessible way, such as in the form of written information and/or video education such as telemonitoring, could be considered[45-47].

This study has several limitations. First, there is always a risk that the results of the questionnaires are biased by socially desirable answers from the participating patients, informal caregivers and care professionals. To reduce this risk of bias a research assistant conducted the questionnaires in case of the patients and informal caregivers and the care professionals received the questionnaires by mail to ensure they filled out the questionnaire without the presence of the researcher. The data of the questionnaires were processed anonymously, but this does not completely eliminate the chance of bias in our data.

Second, the response rate of the care professionals was limited so it is unclear whether the answers are representative for the total group. This might be due to high workload.

Third, we conducted a group interview with a selection of care professionals but not with a selection of patients and informal caregivers. A group interview with patients and

informal caregivers might have provided important additional information on how to improve the intervention.

An important strength of our study is the broad approach of evaluation, which gathered data from care professionals as well as patients and informal caregivers. This study is one of the first in evaluating stroke rehabilitation in older stroke patients.

Despite our intensive collaboration with the stroke care field in developing the program, the results of our process evaluation show that the program was only partly feasible. Implementation research shows that implementing complex interventions like ours is very challenging in an older population[48]. It seems that complex interventions such as this in clinical practice for older stroke patients require a more intensive and stepwise implementation strategy such as described by Luker and Dowding[48,49] This method could be important to increase necessary knowledge of the key elements in the treatment protocol and enhance the collaboration between members of the rehabilitation teams. Furthermore, we recommend to assess the feasibility and effectiveness of this type of complex interventions by using action research, which gives the researcher the possibility to expand pilot testing including a cyclical and flexible process to optimize the intervention during the research period which is not possible when a process evaluation is performed alongside a randomized controlled trial as was the case in our study[49,50].

Conclusion

This study revealed that the feasibility of the new rehabilitation programme needs further attention. Because of the persisting cognitive deficits and specific care needs in our target population some methods such as goal attainment scaling, self-management training and stroke education seemed not feasible in its current form. To optimize feasibility, these elements could be simplified to make them more suitable for the rehabilitation of older patients. In addition, training of care professionals could be improved. We expect that increasing the feasibility of the programme could also further increase its effectiveness. In addition, the action research method could be a useful tool to tailor the programme optimally to the care setting, care professionals and patients involved.

Abbreviations

Not applicable

Declarations

Ethics approval and consent to participate
Ethical approval was provided by the medical ethics committee of Maastricht University Medical Centre (MUMC+), the Netherlands (ISRCTN62286281, NTR2412). All participants gave written informed consent to take part in the study.

Consent for publication
Not applicable.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Authors' contributions

TV, JvH, JV and JS were involved in the design of the intervention, the protocol training, the design of the process evaluation, data collection, and data analysis. TV wrote drafts of the manuscript. JvH supervised data analysis. JvH, JV, CvH, and JS were involved in the interpretation of the results. JvH, JV, and JS supervised the project. All authors read, critically reviewed and approved the final manuscript.

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References

1. Lincoln NB, Gladman JR, Berman P, Noad RF, Challen K: Functional recovery of community stroke patients. Disabil Rehabil 2000, 22(3):135-9.
2. Desrosiers J, Noreau L, Rochette A, Bravo G, Boutin C: Predictors of handicap situations following post-stroke rehabilitation. Disabil Rehab 2002, 24(15):774-85.
3. Dijkerman HC, Wood VA, Hewer RL: Long-term outcome after discharge from a stroke rehabilitation unit. J R Coll Physician Lond 1996, 30(6):538-46.
4. Peerenboom PBG, Spek J, Zekveld I, Cools HJM., Balen R van, Hoogenboom MJ: Revalidatie in de AWBZ, omvang, aard en intensiteit. ETC Tangram/LUMC; 2008.
5. Prevalentie beroerte in huisartsenpraktijk naar leeftijd en geslacht. Jaarprevalentie beroerte 2018. www.volksgezondheidenzorg.info RIVM 2020.
6. Cramer SC: Changes in motor system function and recovery after stroke. Restor Neurol Neurosci 2004, 22(3-5):231-38.
7. D'Alisa S, Baudi S, Mauro A, Miscio G: How does stroke restrict participation in long-term post-stroke survivors? Acta Neurol Scand 2005, 112(3):157-62.
8. Murray J, Ashworth R, Forster A, Young J: Developing a primary care-based stroke service: A review of the qualitative literature. Br J Gen Pract 2003, 53(487):137-42.
9. Morrison V, Pollard B, Johnston M, MacWalter R: Anxiety and depression 3 years following stroke: demographic, clinical, and psychological predictors. J Psychosom Res 2005, 59(4):209-13.
10. Rasquin SM, Lodder J, Ponds RW, Winkens I, Jolles J, Verhey FR: Cognitive functioning after stroke: A one-year follow-up study. Dement Geriatr Cogn Disord 2004, 18(2):138-44.
11. Alawieh A, Zhao J, Feng W. Factors affecting post-stroke motor recovery: Implications on neuro-therapy after brain injury. Behav Brain Res. 2018 Mar 15;340:94-101.
12. Rosenich E, Hordacre B, Paquet C, Koblar SA, Hillier SL. Cognitive Reserve as an Emerging Concept in Stroke Recovery. Neurorehabil Neural Repair. 2020 Mar;34(3):187-199.
13. van Heugten C, Visser-Meily A, Post M, Lindeman E: Care for carers of stroke patients: evidence-based clinical practice guidelines. J Rehabil Med 2006, 38(3):153-8.

6

14. Oliva-Moreno J, Peña-Longobardo LM, Mar J, Masjuan J, Soulard S, Gonzalez-Rojas N, Becerra V, Casado MÁ, Torres C, Yebenes M, Quintana M, Alvarez-Sabín J; CONOCES Investigators Group. Determinants of Informal Care, Burden, and Risk of Burnout in Caregivers of Stroke Survivors: The CONOCES Study. Stroke. 2018 Jan;49(1):140-146.

15. Bollars S, van Erp J, Fens M, van Gorp E, van Hoppe J, Krikke T, de Meris, J, Notz B, van der Ven A, Vluggen T, Benjaminsen S: Uitbehandeld! Hoezo? Een leidraad in het doolhof van zorg in de chronische fase na een CVA. Kennisnetwerk CVA Nederland; 2012.

16. Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF: Therapy-based rehabilitation services for patients living at home more than one year after stroke. Cochrane Database Syst Rev 2008, 16(2):CD005952.

17. Fens M, Vluggen T, van Haastregt JC, Verbunt JA, Beusmans GH, van Heugten CM. Multidisciplinary care for stroke patients living in the community: a systematic review. J Rehabil Med. 2013 Apr;45(4):321-30.

18. Mulder AHM, De Witte LP, Diederick JPM. Evaluation of a rehabilitation after-care programme for stroke patients. Journal of Rehabilitation Sciences 1989;2(4):97–103.

19. Lincoln NB, Walker MF, Dixon A, Knights P. Evaluation of a multi-professional community stroke team: a randomized controlled trial. Clinical Rehabilitation 2004;18:40–7.

20. Allen KR, Hazelett S, Jarjoura D, Wickstrom GC, Hua K, Weinhardt J, Wright K. Effectiveness of a post-discharge care management model for stroke and transient ischemic attack. A randomised trial. J Stroke Cerebrovasc Dis 2002;11:88-98.

21. Allen K, Hazelett S, Jarjoura D, Hua K, Wright K, Weinhardt J, Kropp D. A randomised trial testing the superiority of a postdischarge care management model for stroke survivors. J Stroke Cerebrovasc Dis 2009;18:443-52.

22. Gladman JR, Lincoln NB. Follow-up of a controlled trial of domiciliary stroke rehabilitation (domino study). Age Ageing 1994;23:9-13.

23. Bjorkdahl A, Nilsson AL, Grimby G, Sunnerhagen KS. Does a short period of rehabilitation in the home setting facilitate functioning after stroke? A randomised controlled trial. Clin Rehab 2006;20:1038-49.

24. Burton C, Gibbon B. Expanding the role of the stroke nurse: A pragmatic clinical trial. J Adv Nurs 2005;52:640-50.

25. Forster A, Young J, Green J, Patterson C, Wanklyn P, Smith J, Murray J, Wild H, Bogle S, Lowson K. Structured re-assessment system at 6 months after a disabling stroke: A randomised controlled trial with resource use and cost study. Age Ageing 2009;38:576-83.

26. Gladman JR, Lincoln NB, Barer DH. A randomised controlled trial of domiciliary and hospital-based rehabilitation for stroke patients after discharge from hospital. J Neurol Neurosurg Psychiatry 1993;56:960-6.

27. Mayo NE, Nadeau L, Ahmed S, White C, Grad R, Huang A, Yaffe MJ, Wood-Dauphinee S. Bridging the gap: The effectiveness of teaming a stroke coordinator with patient's personal physician on the outcome of stroke. Age Ageing 2008;37:32-8.

28. Roderick P, Low J, Day R, Peasgood T, Mullee MA, Turnbull JC, Villar T, Raftery J. Stroke rehabilitation after hospital discharge: A randomized trial comparing domiciliary and day-hospital care. Age Ageing 2001;30:303-10.

29. Ryan T, Enderby P, Rigby AS. A randomised controlled trial to evaluate intensity of community-based rehabilitation provision following stroke or hip fracture in old age. Clin Rehab 2006;20:123-31.

30. Ytterberg C, Anderson Malm S, Britton M. How do stroke patients fare when discharged straight to their homes? A controlled study on the significance of hospital follow-up after one month. Scand J Rehabil Med 2000;32:93-6.

31. Markle-Reid M, Orridge C, Weir R, Browne G, Gafni A, Lewis M, Walsh M, Levy C, Daub S, Brien H, Roberts J, Thabane L. Interprofessional stroke rehabilitation for stroke survivors using home care. Can J Neurol Sci. 2011;38(2):317-34.

32. Vluggen TP, Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012 Dec 31;12(1):164.

33. Saunders RP, Evans MH, Joshi P. Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. Health Promot Pract. 2005 Apr;6(2):134-47.

34. Oakley A, Strange V, Bonell C, Allen E, Stephenson J; RIPPLE Study Team.
Process evaluation in randomised controlled trials of complex interventions. BMJ. 2006 Feb 18;332(7538):413-6.

35. Rockwood K, Stolee P, Fox R: Use of goal attainment scaling in measuring clinically important change in the frail elderly. J Clin Epidemiol 1993, 46(10):1113–1118.

36. Debreceni-Nagy A, Horváth J, Nagy S, Bajusz-Leny Á, Jenei Z. Feasibility of six-point Goal Attainment Scale among subacute and chronic stroke patients. Int J Rehabil Res. 2019 Dec;42(4):365-370.

37. Walker MF, Leonardi-Bee J, Bath P, Langhorne P, Dewey M, Corr S, Drummond A, Gilbertson L, Gladman JR, Jongbloed L, Logan P, Parker C: Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. Stroke 2004, 35(9):2226–2232.

38. Fjaertoft H, Indredavik B, Lydersen S: Stroke unit care combined with early supported discharge: long-term follow-up of a randomized controlled trial. Stroke 2003, 34(11):2687–2691.

39. Fjærtoft H, Rohweder G, Indredavik B. Stroke unit care combined with early supported discharge improves 5-year outcome: a randomized controlled trial. Stroke. 2011 Jun;42(6):1707-11.

40. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR: Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 2001, 39(11):1217–1223.

41. Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? Disabil Rehabil 2006, 28(13–14):841–847.

42. Shulman LM, Velozo C, Romero S, Gruber-Baldini AL. Comparative study of PROMIS® self-efficacy for managing chronic conditions across chronic neurologic disorders. Qual Life Res. 2019 Jul;28(7):1893-1901.

43. Moulaert VR, van Haastregt JC, Wade DT, van Heugten CM, Verbunt JA. 'Stand still …, and move on', an early neurologically-focused follow-up for cardiac arrest survivors and their caregivers: a process evaluation.

44. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database Syst Rev. 2003. p. CD002925.

45. Bernocchi P, Vanoglio F, Baratti D, Morini R, Rocchi S, Luisa A, Scalvini S. Home-based telesurveillance and rehabilitation after stroke: a real-life study. Top Stroke Rehabil. 2016 Apr;23(2):106-15.

46. Sarfo FS, Ulasavets U, Opare-Sem OK, Ovbiagele B. Tele-Rehabilitation after Stroke: An Updated Systematic Review of the Literature. J Stroke Cerebrovasc Dis. 2018 Sep;27(9):2306-2318.

47. Lawson DW, Stolwyk RJ, Ponsford JL, McKenzie DP, Downing MG, Wong D. Telehealth Delivery of Memory Rehabilitation Following Stroke. J Int Neuropsychol Soc. 2020 Jan;26(1):58-71.

48. Luker JA, Craig LE, Bennett L, Ellery F, Langhorne P, Wu O, Bernhardt J. Implementing a complex rehabilitation intervention in a stroke trial: a qualitative process evaluation of AVERT. BMC Med Res Methodol. 2016 May 10;16(1):52.

49. Dowding D, Lichtner V, Closs SJ. Using the MRC Framework for Complex Interventions to Develop Clinical Decision Support: A Case Study. Stud Health Technol Inform. 2017;235:544-548.

6

50. Taylor J, Coates E, Wessels B, Mountain G, Hawley MS. Implementing solutions to improve and expand telehealth adoption: participatory action research in four community health care settings. BMC Health Serv Res. 2015 Dec 1:15:529.

CHAPTER 7

General discussion

Introduction

The research presented in this dissertation had four main objectives. The first objective was to develop an integrated geriatric rehabilitation programme to improve daily activity, functional independence, perceived quality of life and social participation of older stroke patients, and to have a favourable impact on the care burden and quality of life of informal caregivers[1]. The second objective was to identify factors, measured at admission to geriatric rehabilitation, which are associated with home discharge, among frail and multimorbid older stroke patients [2]. The third objective was to evaluate the effects of the integrated geriatric rehabilitation programme on daily activity, functional independence, perceived quality of life and social participation of older stroke patients, and on the care burden and quality of life of their informal caregivers[3]. The fourth objective was to gain insight in the feasibility of the programme by assessing: 1) to what extent the integrated multidisciplinary rehabilitation programme was performed according to protocol; 2) to evaluate the participation of the patients in the programme; and 3) to assess the opinion of patients, informal caregivers and care professionals on the programme[4].

In this chapter, the main findings of the research and their implications are discussed. Strengths and limitations of the studies are reflected on, and implications for clinical practice future research are presented.

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Main findings

Development of the integrated geriatric rehabilitation programme

The integrated programme for patients and informal caregivers was based on evidence from literature and expert opinion of stroke professionals, stroke patients and informal caregivers (chapter 4). The systematic review[5] (chapter 2) and interview sessions with the stroke experts, which we performed prior to the start of the study, led to a multidisciplinary programme adding the following key elements to usual care: formulating multidisciplinary rehabilitation goals by using the goal attainment scaling method[6], therapy sessions at the patient's home[7,8], self-management training for patients and informal caregivers[9,10], stroke education for patients and informal caregivers[11], and guidance and support by a stroke coordinator for patients and informal caregivers[12]. The integrated programme is organised in three care modules: 1) inpatient neurorehabilitation treatment for patients; 2) home-based self-management training and support for patient and informal caregiver; and 3) stroke education for patient and informal caregiver. To facilitate optimal communication and information exchange between the care

professionals involved an electronic transmural patient record was available for the care professionals delivering the treatment of the stroke patients and informal caregivers participating in the new integrated geriatric rehabilitation programme.

Effectiveness of the integrated geriatric rehabilitation programme

The multicentre randomized controlled trial to evaluate the effects of the new integrated geriatric rehabilitation programme (chapter 5)[3], showed that the programme had no effect on the primary outcome parameter daily activity as compared to usual care. However, the intervention did show a statistically significant favourable effect on autonomy regarding outdoor activities as perceived by the patients. Furthermore, we also found a statistically significant favourable effect on the perceived care burden of informal caregivers. For the other secondary outcomes, no significant intervention effects were observed.

Feasibility of the integrated geriatric rehabilitation programme

The process evaluation performed alongside the multicentre randomized controlled trial, revealed that although the rehabilitation programme was overall well received, the feasibility of the programme needs further attention (Chapter 6)[4]. Some widely used methods in rehabilitation, such as goal attainment scaling, self-management training and stroke education seemed only partly feasible among our population of frail and multimorbid older stroke patients. These feasibility problems seemed to be related to the persisting cognitive deficits and specific care needs of frail older stroke patients, which made it difficult for care professionals to carry out these elements of the programme as planned. To optimize the feasibility of the programme, these elements could be simplified to make them more suitable for the rehabilitation of frail older patients. In addition, training of care professionals could be improved.

Factors related to home discharge after inpatient geriatric rehabilitation

Based on relationships with home discharge of stroke patients identified in previous research, and availability of variables in our randomized controlled trial, 16 variables measured at admission to inpatient geriatric rehabilitation, were identified as factors potentially associated with home discharge after inpatient rehabilitation among frail and multimorbid older stroke patients (chapter 3)[2]. Factors involved were age, sex, household situation before admission (living alone or with others), stroke history, cognitive disability, neglect, apraxia, dysphagia, urinary and bowel incontinence, sitting balance, emotional problems, cardiovascular disorders, diabetes mellitus, multimorbidity, daily activity level, and independence in activities of daily living. The results of our prognostic study indicated that 15 of these 16 factors were not significantly related to home discharge among our group of frail and multimorbid older persons admitted

to geriatric rehabilitation after stroke. Only one factor, a pre-existing higher level of independence in activities of daily living at admission, was significantly related to home discharge.

Reflection

This paragraph provides a reflection on several aspects relating to the effectiveness and feasibility of the integrated geriatric rehabilitation programme for older stroke patients.

Effects of the integrated geriatric rehabilitation programme

As indicated above no statistically significant effect of the integrated programme, was observed in the current study for the primary outcome daily activity level (FAI). Various studies have indicated that improving performance on daily activities seems to be rather difficult in many frail older stroke patients[5,8,13]. An important explanation for this seem to be the irreversible functional and cognitive limitations caused by stroke in combination with multimorbidity and other age related problems[3,13,14]. Inactivity is a very common problem in older stroke patients and remains a challenge because literature is not conclusive about interventions improving daily activity. To increase the activity level it is important to pay attention to increasing activity and participation level despite of the restrictions caused by stroke combined with multimorbidity and other age related challenges[15,16]. Our study showed that although our integrated programme was developed for this group of frail older stroke patients, it still did not sufficiently contribute to improving daily activity. This might be partly explained by the fact that some elements of the intervention were not implemented according to plan (see feasibility paragraph below). Another explanation might be that the intervention, although based on literature review and expert opinion, was still not tailored enough to the complex problems within this frail older stroke population.

Achieving a higher activity level in older stroke patients remains a challenge but recent research recommends that: 1) goal setting should be facilitated by a trained facilitator using the Canadian Occupational Performance Measure (COPM) to give tailored direction to the goals[17-19]; 2) researchers and care professionals should learn from each other's experiences, and use that for further improvement of care programmes[17-19]; and 3) self-management programmes for older stroke survivors in order to support the self-management skills of the patients should include personalized support from family, friends and/or health professionals[17-19]. These three elements seem to achieve a greater activity and participation level in older stroke patients specifically enhancing confidence, competence, and self-efficacy[17-19]. Furthermore, recent research among frail older stroke

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patients suggests that group therapy in the form of circuit training after stroke, seems to be promising in improving activity level, but still more research is needed to investigate the optimal exercise prescription and the long term effects[20].

Although in the current study no favourable effects of the integrated programme were observed for daily activity, our programme had a favourable effect on perceived autonomy of outdoor activities, indicating that patients receiving the programme perceived more abilities to participate independently in outdoor activities. Furthermore, a statistically significant reduction was observed for the perceived care burden of informal caregivers. A reduction of the (perceived) care burden of informal caregivers of stroke patients seem very relevant because a study of van Heugten et al. among stroke patients revealed that almost 80% of the informal caregivers of stroke patients after discharge from rehabilitation reported a very high care burden[21].

These positive effects on autonomy and care burden may be explained by the fact that the self-management programme may have improved the coping skills and resilience of patients and informal caregivers. This might have helped them to develop more realistic expectations about the patients activities in light of their residual health problems. In addition, increased coping skills and resilience of both patients and informal caregivers might on the one hand have reduced the perceived care burden of informal caregivers by offering them tools to better cope with the daily challenges of stroke related impairments[22,23]. On the other hand, it might have empowered patients to achieve specific goals in life despite their (stroke related) impairments.

Feasibility of the integrated geriatric rehabilitation programme

Below the feasibility of the main elements of the programme are discussed: goal attainment scaling; home-based therapy; self-management; and stroke education.

- *Goal attainment scaling*

To optimize the functional level of stroke patients, at the start of our study goal attainment scaling was considered in the international literature to be an effective method to use in rehabilitation for goal setting and to quantify the level of achievement[6]. Our intervention was developed in close collaboration which stroke professionals in geriatric rehabilitation who also considered goal attainment scaling to be a potentially effective method to use for goal setting in geriatric rehabilitation. However, our process-evaluation showed that the feasibility of using goal attainment scaling among this frail older population of stroke patients was perceived as limited according to the care professionals using it to set goals with their patients. Although, goal setting is an important part of geriatric rehabilitation, it seems a challenge for care professionals to

support their patients in formulating rehabilitation goals[17,24]. Although we aimed to tailor the goal attainment method to our frail older population by simplifying it on several aspects, the method was still perceived as rather complex and difficult for older stroke patients to use. Recent research also points on the difficulties of goal attainment scaling in the older population to use for goal setting which makes it a challenge to find suitable alternatives[15,16,24,25]. However, it is recommended to use a form of goal attainment scaling because it seems to be an important instrument for the rehabilitation of stroke survivors[26]. A possible method to better tailor goal setting to our target population, could be by using pictures with the most relevant rehabilitation goals presented like the Photograph Series of Daily Activities (PHODA) method used among patients with low back pain which gives the patient support in choosing their own rehabilitation goals[27]. To develop a method optimally tailored to the needs and potential goals of frail older stroke patients, it seems important to gain additional insight in their needs and goals and to assess the feasibility and effectiveness of this approach for goal setting among frail older stroke patients.

An additional method that may be used for improving goal setting in older stroke patients is the use of Patient-Reported Outcome Measures (PROMs). PROMs can be used to help monitoring and evaluating the improvement in health and well-being of individual patients during rehabilitation[28-30]. The PROMIS-PF-GR, a 24 item PROM has been specifically developed for the geriatric population and can measure physical function to monitor the rehabilitation progress[31]. According to Vermunt and colleagues, PROMs seem to be clinically meaningful and can help to give better direction in making realistic rehabilitation goals. Furthermore, according to Vermunt the effects and feasibility of collaborative goal setting, should be assessed among the population of frail older stroke patients. This approach in which stroke professionals, patients and informal caregivers develop rehabilitation goals together, seems to be an effective method, especially for cognitively impaired patients[31].

- *Home therapy*

Home therapy has shown to be effective in facilitating early discharge and to enhance and sustain the functional capabilities of older patients after inpatient rehabilitation[7,8]. Recent research among older stroke patients underlines the importance to start with home therapy as early as possible after geriatric rehabilitation to reduce disability and increase quality of life[26]. However, our process evaluation showed that, it was considered difficult by the care professionals involved in our integrated programme, to organise home therapy for all patients during their stay in the geriatric rehabilitation facility and after discharge. Especially, logistic barriers such as travel time to the patients' home were mentioned. Also, the costs of home therapy were mentioned as a barrier, despite the fact that the therapists participating in the programme received financial compensation

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for travel time and costs. Although, since the start of our study in 2010 a number of changes have been implemented in the Dutch care setting regarding, rules, regulations and reimbursement of geriatric rehabilitation, the barriers mentioned by the care professionals participating in our study, seem still to be relevant in the current situation.

To improve the feasibility of home therapy and decrease the time and cost barriers mentioned, telerehabilitation might be an effective future method for therapists to train and support discharged patients more from a distance. Recent research shows that telerehabilitation can improve functioning among older stroke patients, it may reduce rehabilitation costs and also the care burden of the informal caregiver[32,33]. The use of telerehabilitation seems to be beneficial to maintain the functional capacity of frail older stroke patients after rehabilitation compared to conventional face to face therapy[34,35]. Telerehabilitation will certainly not be suitable for all frail older stroke patients yet, but it has potential for the future, because the future population of older people is expected to be much more experienced with technology and smart devices, compared to the current generation of older persons. Furthermore, the type and amount of guidance offered by care professionals to patients using telerehabilitation, should be tailored optimally to the needs and skills of the individual patient. Additional research is needed to assess the feasibility and effectiveness of this tailored guided telerehabilitation among frail older stroke patients.

- *Self-management training*

The use of self-management training has proven to be effective in enhancing problem solving skills and related social participation in older patients affected by a chronic condition such as stroke[9,10,36]. The main goal of self-management is to empower patients to manage their medical condition, maintain or change their behaviours and social roles, and deal with the emotional consequences of surviving stroke[7]. In addition, it can help to prevent permanent admission to a nursing home[1]. However, the care professionals in our study considered the self-management method used to stimulate patients in their problem-solving skills as rather complex and difficult to apply for frail older stroke patients. Although evidence from literature suggests that this self-management method can manage the impact of stroke in terms of symptoms, behaviour and also participation, the effects in our population seemed limited[37]. Results of our process evaluation showed that the stroke professionals experienced that within the self-management process it is difficult to develop action plans with realistic rehabilitation goals with older stroke patients who often have cognitive impairments. Although it is important for the empowering process that patients and informal caregivers actively participate in the formulation of goals and action plan because collaborative goal setting is proven to be effective[31]. The stroke professionals who participated in our study indicated that more

intensive guidance is needed to help patients and informal caregivers to formulate rehabilitation goals and action plans.

Further to improve the feasibility of self-management in older frail stroke patients it seems important to increase self-efficacy. According to Nott and colleagues self-efficacy is considered to be an important element for successful rehabilitation outcome because it gives the patient the belief to be in control of their own motivation, behaviour and social environment[17]. Self-efficacy could be improved by one-on-one guidance from a therapist which includes helping the patient in the process of goal setting and problem solving[17-19]. The one-on-one coaching method which includes more intensive guidance by a stroke professional could be an important element which might improve the feasibility and effectiveness of our programme. Furthermore, research of Kessler and colleagues indicates that improving the self-efficacy and self-management skills of the patient are very important but these could be hindered by stroke related impairments[18,19]. Therefore, we suggest that it might be important to also aim the intervention at the strengths and skills of informal caregivers. In our intervention we tried to train informal caregivers but more intensive training of informal caregivers in problem-solving skills, coping skills and other methods to reduce care burden seems to be necessary and could be effective in empowering the home living situation of patient and caregiver together. In order to further optimize the self-management training for frail older stroke patients and their informal caregivers, it seems essential to involve (representatives) of this group in the development of optimized strategies, in order to optimally tailor it to their needs and skills.

- ● *Stroke education*

In our study, we provided relevant information on stroke rehabilitation to empower patients and their informal caregivers. The aim of this stroke education was to provide the patient and caregiver with information about their disease that can help to increase self-management skills. Patients and their caregivers were invited to join the educational sessions. However, only about a quarter of the patients and informal caregivers attended the education sessions in our study. Main reasons for this low level of attendance, as reported by patients and their informal caregivers were lack of time, lack of interest, and problems with travelling to the facility. However, a majority of patients, informal caregivers and care professionals who participated in the programme indicated the beneficial aspects of the stroke education. Therefore, it seems important to offer the stroke education in a more accessible and feasible way. The insights gained during the COVID-19 pandemic showed that the use of e-Health among this population could be considered as a method that could be considered for stroke education [34,38-40]. Future research, in which patients, informal caregivers and care professionals closely collaborate, should

provide more insight in the feasibility and effectiveness of e-Health for educational purposes in stroke rehabilitation among older patients.

Factors related to home discharge after inpatient geriatric rehabilitation

At admission to an intermediate care facility for geriatric rehabilitation it is important to make a well-founded prognosis about the chances of a patient to return to the former living situation after inpatient rehabilitation and to support them to focus their treatment on increasing the chances of home discharge[2,41]. However, our study showed that adequately predicting functional recovery and home discharge for the group of frail older stroke patients in our study, is a challenge. In contrast to research in the general population of stroke patients, our study revealed that only a higher level of independence in activities of daily living at admission was significantly related to home discharge, indicating that it is important to assess this outcome during the screening and admission process of older stroke patients. The other 15 potential predictors of home discharge we assessed, were not related to home discharge. It therefore seems that in a frail, older, multimorbid population like in our study other factors which were not often included in previous prognostic studies (mostly focussing on younger stroke patients), might play a role in home discharge, such as frailty, cognitive functioning, (post stroke) depression, resilience, and availability and readiness of informal caregivers to support the patient at home[1,14,22,23,42,43].

Future research should include these factors to explore their relationship with home discharge, because in current geriatric rehabilitation practice they seem very important in the decision making process regarding discharge location[14,42,43]. Especially the availability and readiness of the informal caregivers seems to be a very important and decisive factor in the discharge process of older persons after stroke rehabilitation[43,44].

Methodological considerations

This paragraph discusses the methodological strengths and limitations of our study related to the study design, the study population and the generalizability of the results.

Study design

The randomised controlled trial (RCT) is considered to be the most powerful study design due to the high internal validity and because of the lower risk of bias[45]. However, RCTs are strictly protocolized and do not allow any intermediate modifications in treatment procedures, based on new insights and experiences during the trial. In frail, older, multimorbid, populations such as the population in the current study, it seems very

challenging to optimally tailor the programme to the target population. It is therefore recommended to take sufficient time for the development process of intervention programmes within these challenging populations and to closely collaborate with the often heterogeneous patient population, and the other relevant stakeholders including informal caregivers, care professionals, managers and health care insurers. One way to achieve this is to choose research designs that offer more possibilities for co-creation and intermediate modifications of the intervention programme, such as participatory action research[46]. This type of research provides researcher the opportunity to adapt the program during the study in close collaboration with the target population (i.e. patients, informal caregivers and care-professionals), and to tailor it optimally to the setting and population. Using the action research method could lead to better implementation, better commitment of health care professionals, better tailoring of the intervention to the needs and skills of the users and better effectiveness of the intervention[47].

Study population

Most older stroke patients are persons with complex health problems and multiple morbidities. In general, patients in this group are frail which results in challenges in the recruitment and (follow-up) measurements of participants, as was also the case in the present study. This problem is inevitable when doing research in frail older populations, and due to the aging of the population this problem is expected to increase the next decades. Within the present study we have taken various measures to prevent our study participants from dropping out of the research, in the form of sending written reminders, making phone calls to complete missing values in questionnaires, gathering most data among the patients by means of interviews (instead of questionnaires), and using clear and understandable language in the communication with patients and informal caregivers. For future research among this frail older population and their (also often older) informal caregivers, it remains important to anticipate on larger drop-out rates (of approximately 25% or more) in order to prevent methodological problems. In addition, more insight should be gained in ways to minimize drop-out rates among frail older populations. Besides this, it remains highly important to accurately analyse potential sources of bias in case of drop-out[47]. In addition, besides the use of quantitative research methods, also the use of small scale qualitative methods using purposive sampling techniques should be considered, in which rich data can be gathered among a relatively small group of patients. This type of qualitative research, could be highly valuable in gaining insight in how to better tailor geriatric rehabilitation approaches to the needs and skills of frail older stroke patients.

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Generalizability

This integrated geriatric rehabilitation programme was developed in the south of the Netherlands in strong collaboration with experts in the field of geriatric stroke rehabilitation.

Although there was broad consensus among the experts (including care professionals, and representatives of patients and informal caregivers) about the content of the rehabilitation programme the process evaluation (chapter 4) showed that some key elements of the programme should be further optimised in future research to tailor them better to the needs of frail older stroke population with multiple health problems. Especially some key elements such as goal attainment scaling, self-management training and stroke education seemed not sufficiently feasible in its current form for our target population.

Despite the limitations of the programme, the observed effects seem to be representative for the Dutch stroke rehabilitation setting in the period 2010 to 2014 and can therefore be used to further optimize stroke care. However, since the start of our study in 2010, geriatric rehabilitation care for older stroke patients has continued to develop and new insights have occurred both in the Netherlands as internationally. Increasingly programme elements such as goal setting, self-management, home-based therapy and stroke education are considered relevant and potentially effective [17, 48-51]. However, the way in which the programme elements should be offered to frail older stroke patients still requires additional research. Future research should focus on better tailoring the key elements of our intervention to the target population, and also defining best practices in care, necessary expertise, and improving regional stroke care collaborations to improve the effectiveness and feasibility of stroke rehabilitation for frail older patients[52].

Because of the substantial differences between geriatric rehabilitation treatment across countries, caution should be taken when generalizing the results of the present study to other countries or populations[53,54].

Implications for clinical practice

The results of our trial show that implementation of the integrated rehabilitation programme leads to a higher level of perceived autonomy of outdoor activities among patients and a lower perceived care burden for informal caregivers. This indicates that the programme is promising but needs further adaption before implementation in stroke rehabilitation.

Results of our process evaluation showed that although there was broad consensus on the content of the programme at the start of the study, not all elements of the programme were considered feasible and were not conducted according to the intervention protocol. It is recommended to more intensively collaborate with patients and their informal caregivers by involving them in a process of co-creation of treatment programmes, for example in the form of participatory action research. Furthermore, it is recommended to intensify the collaboration between researchers and care professionals within the domain of geriatric stroke rehabilitation both in the Netherlands as internationally. It is important to learn from each other experiences and to translate these experiences and the available research evidence into feasible guidelines and care pathways[52].

Regarding the specific elements of our integrated programme several recommendations can be made. With regard to home therapy, it can be concluded that in the Netherlands currently, the use of home-based therapy is still rather limited in geriatric rehabilitation. This indicates that still considerable practical barriers are experienced in the use of home-based therapy. It is recommended that geriatric rehabilitation facilities are going to perform small scale pilots to gain more experience with the organisation of home based geriatric rehabilitation and to gain more insight in its barriers and facilitators and its potential advantages and disadvantages for patients. Results of these pilots should be shared with their colleagues on a national basis, so that organisations can learn from each other's experiences'. Furthermore, the insights gained during the COVID-19 pandemic on the use of e-Health among this population should be integrated in these pilots[40]. Collaboration with health care insurers within these pilots is important in order to try to solve the perceived problems regarding the current regulations regarding the of reimbursement of home-based therapy in geriatric rehabilitation[32,33]. In addition, collaboration with researchers (e.g. within the currently present living labs) can be sought for advice regarding the monitoring of results of the pilots.

Regarding self-management training, the present study revealed that the care professionals involved considered it rather complex and difficult to apply among frail older persons with stroke. A possible new approach to make self-management training more successful is to use the more intensive one-on-one coaching method to improve the feasibility and effectiveness of our programme[17-19].

The use of an electronic patient record is an important tool to optimize communication, work efficiency, and collaboration between care professionals during rehabilitation. For that reason it is essential to use an integrated patient record for inpatient and outpatient rehabilitation to share information about the patient's treatment (with consensus of the patient).

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Regarding the prognosis of the rehabilitation outcome at admission, our analyses showed that only a pre-existing higher level of independence in activities of daily living at admission to geriatric rehabilitation is associated with discharge to the former living situation. Therefore, it is recommended that care professionals check the current level of independence in daily living at admission to geriatric rehabilitation. Especially for patients with relatively low scores on independence in activities of daily living it is recommended to focus more strongly during treatment on increasing the level of independence in activities of daily living and to assess in close collaboration with the patients and their informal caregivers, which skills and support they need to regain their independence and to be able to return home. Furthermore, it is recommended to broaden the perspective to additional factors which might be important in predicting treatment outcome, such as frailty, cognitive functioning, (post stroke) depression, resilience, and availability and readiness of informal caregivers to support the patient at home[1,22,23].

Finally, we recommend care professionals to provide stroke education to the patients and their relatives in a way that is optimally tailored to the needs and skills of the patients (because one size does not fit all). This means that several options might be offered to patients and their relatives such as face to face meetings, video's, written materials and short e-learning modules[17-19]. Again co-creation with patients and their relatives is highly recommended in order to optimally tailor the education to their needs and skill. Furthermore, collaboration between geriatric rehabilitation facilities is recommended so that materials can be exchanged between organisations or can be developed and/or acquired collectively.

Implications for future research

Based on the present study several recommendations can be made.

First, due to the high drop-out rate in research among frail older populations, it is important to gain more insight in reasons of drop-out and ways to reduce the risk of drop-out in research among frail older populations.

Second, we recommend to further explore the potential feasibility and effectiveness of the key elements of the integrated geriatric rehabilitation in future studies (formulating multidisciplinary rehabilitation goals by using the goal attainment scaling method[6], therapy sessions at the patient's home[7,8], self-management training for patients and informal caregivers[9,10], stroke education for patients and informal caregivers[11], and

guidance and support by a stroke coordinator for patients and informal caregivers[12]). For this studies preferably research designs should be used that provide the opportunity for exploration, cyclic (pilot)testing, and close collaboration with patients, informal caregivers, care professionals and care organisation. This could be conducted in the form of small scale qualitative case studies in close collaboration with care organisations and participatory action research. Furthermore, it is recommended to include other potentially relevant predictors and outcome measures in future research among older stroke patients, such as frailty, resilience, perceived autonomy, and availability and readiness of informal caregivers to support the patient at home[22,23].

Third, goal setting remains an important challenge in the rehabilitation of frail stroke patients. To optimize the empowering process research indicates that patients and informal caregivers should actively participate in the formulation of goals and designing action plans by collaborative goal setting. Future research should, in co-creation with patients, informal caregivers and care professionals, focus on improving the individual goal setting methods by integrating effective collaboration methods between care professionals and patients which can help in making realistic goals during rehabilitation and after discharge[24,25,31].

Fourth, it is important to investigate in which format the self-management support should be offered to increase feasibility in patients in chronic conditions such as stroke[55]. Co-creation and extensive feasibility testing , for example in the form of action research, should be advised to optimise acceptance and effectiveness of the self-management support[56].

Fifth, research indicates that training the informal caregiver in case of severe limitations of the patients could be an effective approach to increase the extend of self-management. Future research should focus on the development of training programs for informal caregivers in problem-solving skills, coping skills and other methods to reduce care burden. These programs should be developed in co-creation with the target population and could be effective in empowering the home living situation of patient and caregiver.

Finally, it is important that future programmes (which have proven to be effective and feasible) are implemented correctly. A correct implementation of new programmes is a challenge and care organisations should be supported in this process, for example by being offered practical implementation tools and clearly described guidelines, pathways or protocols. As recommended by Wensing and colleagues, it is important to inform, motivate and train professionals to increase insight in the current performance, and to set clear targets for change[57]. Furthermore, Wensing and colleagues suggest to tailor

the implementation process to the target population(s) by analyzing possible barriers and to select strategies which increase implementation. The selected strategies and measurements should be part of the implementation plan which must be pilot tested, if necessary adapted and executed. Finally the changes must be integrated in usual care and continuous evaluated and if necessary adapted.

Conclusion

An integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke was developed in 2010 based on the literature and in collaboration with experts in the stroke field and implemented in eight geriatric rehabilitation units in the Netherlands. The programme aimed to improve the activity level, functional independence, perceived quality of life and social participation of patients and to positively impact care burden and quality of life of their informal caregivers. The results of a randomized controlled trials showed that the integrated multidisciplinary programme had no effect on daily activity, functional dependence, and perceived quality of life of older stroke patients. However, patients participating in the programme had a higher level of perceived autonomy of outdoor activities and their formal caregivers perceived a lower care burden.

The programme might be promising in providing adequate stroke (after)care for frail older stroke patients, although adaptation of the programme is recommended to increase its feasibility and improve its effects on improving rehabilitation outcome. To improve the feasibility and effectiveness of the developed stroke rehabilitation programme important key element such as goal attainment scaling, home therapy, self-management and stroke education need to be better tailored to the needs and skills of the target population. Action research including the co-creation of programme elements with the target population could be a possible useful method for the development of complex stroke interventions such as the intervention of this study. In addition, it is recommended to broaden the scope in these studies by including potentially relevant and previously underexposed predictors and outcomes, such as potentially relevant predictors and outcome measures in future research among older stroke patients, such as frailty, resilience, perceived autonomy, and availability and readiness of informal caregivers to support the patient at home.

References

1. Vluggen TP, van Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural reha- bilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012 Dec 31;12:164.

2. Vluggen TPMM, van Haastregt JCM, Tan FES, Kempen GIJM, Schols JMGA, Verbunt JA. Factors associ- ated with successful home discharge after inpatient rehabilitation in frail older stroke patients. BMC Geriatr. 2020 Jan 23;20(1):25.

3. Vluggen TPMM, van Haastregt JCM, Tan FE, Verbunt JA, van Heugten CM, Schols JMGA. Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial. BMC Geriatr. 2021 Feb 23;21(1):134.

4. Vluggen TPMM, van Haastregt JCM, Verbunt JA, van Heugten CM, Schols JMGA. Feasibility of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients: a process evaluation. BMC Neurol. 2020 May 29;20(1):219.

5. Fens M, Vluggen T, van Haastregt JC, Verbunt JA, Beusmans GH, van Heugten CM. Multidisci- plinary care for stroke patients living in the community: a systematic review. J Rehabil Med. 2013 Apr;45(4):321-30.

6. Rockwood K, Stolee P, Fox R: Use of goal attainment scaling in measuring clinically important change in the frail elderly. J Clin Epidemiol 1993,46(10):1113–1118.

7. Fjaertoft H, Indredavik B, Lydersen S. Stroke unit care combined with early supported discharge: long-term follow-up of a randomized controlled trial. Stroke. 2003;34(11):2687–2691.

8. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Co- chrane Database Syst Rev. 2003. p. CD002925.

9. Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? Disabil Rehabil. 2006;28(13–14):841–847.

10. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR. Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care. 2001;39(11):1217–1223.

11. Mulder AHM, De Witte LP, Diederick JPM. Evaluation of a rehabilitation after-care programme for stroke patients. Journal of Rehabilitation Sciences 1989;2(4):97–103.

12. Burton C, Gibbon B. Expanding the role of the stroke nurse: A pragmatic clinical trial. J Adv Nurs 2005;52:640-50.

13. Shaw L, Bhattarai N, Cant R, Drummond A, Ford GA, Forster A, Francis R, Hills K, Howel D, Laverty AM, McKevitt C, McMeekin P, Price C, Stamp E, Stevens E, Vale L, Rodgers H. An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT. Health Technol Assess. 2020 May;24(24):1-202.

14. van Almenkerk S, Smalbrugge M, Depla MF, Eefsting JA, Hertogh CM. What predicts a poor outcome in older stroke survivors? A systematic review of the literature. Disabil Rehabil. 2013 Oct;35(21):1774- 82.

15. Selenitsch NA, Gill SD. Stroke survivor activity during subacute inpatient rehabilitation: how active are patients? Int J Rehabil Res. 2019 Mar;42(1):82-84.

16. de Graaf JA, van Mierlo ML, Post MWM, Achterberg WP, Kappelle LJ, Visser-Meily JMA. Long-term restrictions in participation in stroke survivors under and over 70 years of age. Disabil Rehabil. 2018 Mar;40(6):637-645.

17. Nott M, Wiseman L, Seymour T, Pike S, Cuming T, Wall G. Stroke self-management and the role of self-efficacy. Disabil Rehabil. 2021 May;43(10):1410-1419.

7

18. Kessler D, Egan M, Dubouloz CJ, McEwen S, Graham FP. Occupational Performance Coaching for Stroke Survivors: A Pilot Randomized Controlled Trial. Am J Occup Ther. 2017 May/Jun;71(3):7103190020p1-7103190020p7.

19. Kessler DE, Egan MY, Dubouloz CJ, Graham FP, McEwen SE. Occupational performance coaching for stroke survivors: a pilot randomized controlled trial protocol. Can J Occup Ther. 2014 Dec;81(5):279-88.

20. Saunders DH, Sanderson M, Hayes S, Johnson L, Kramer S, Carter DD, Jarvis H, Brazzelli M, Mead GE. Physical fitness training for stroke patients. Cochrane Database Syst Rev. 2020 Mar 20;3(3):CD003316.

21. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: evidence-based clinical practice guidelines. J Rehabil Med. 2006 May;38(3):153-8.

22. Angevaare MJ, Roberts J, van Hout HPJ, Joling KJ, Smalbrugge M, Schoonmade LJ, Windle G, Hertogh CMPM. Resilience in older persons: A systematic review of the conceptual literature. Ageing Res Rev. 2020 Nov;63:101144.

23. van Abbema R, Bielderman A, De Greef M, Hobbelen H, Krijnen W, van der Schans C. Building from a conceptual model of the resilience process during ageing, towards the Groningen Aging Resilience Inventory. J Adv Nurs. 2015 Sep;71(9):2208-19.

24. Smit EB, Bouwstra H, Hertogh CM, Wattel EM, van der Wouden JC. Goal-setting in geriatric rehabilitation: a systematic review and meta-analysis. Clin Rehabil. 2019 Mar;33(3):395-407.

25. Plant S, Tyson SF. A multicentre study of how goal-setting is practised during inpatient stroke rehabilitation. Clin Rehabil 2018; 32(2): 263–272.

26. Rasmussen RS, Østergaard A, Kjær P, Skerris A, Skou C, Christoffersen J, Seest LS, Poulsen MB, Rønholt F, Overgaard K. Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: a randomised controlled trial. Clin Rehabil. 2016 Mar;30(3):225-36.

27. Oliveira CB, Franco MR, Demarchi SJ, Smeets RJEM, Huijnen IPJ, Morelhão PK, Hisamatsu TM, Pinto RZ. Psychometric Properties of the Photograph Series of Daily Activities-Short Electronic Version (PHODA-SeV) in Patients With Chronic Low Back Pain. J Orthop Sports Phys Ther. 2018 Sep;48(9):719-727.

28. Bingham CO 3rd, Noonan VK, Auger C, Feldman DE, Ahmed S, Bartlett SJ. Montreal Accord on Patient-Reported Outcomes (PROs) use series - Paper 4: patient-reported outcomes can inform clinical decision making in chronic care. J Clin Epidemiol. 2017 Sep;89:136-141.

29. Greenhalgh J, Gooding K, Gibbons E, Dalkin S, Wright J, Valderas J, Black N. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. J Patient Rep Outcomes. 2018 Sep 15;2:42.

30. Smit EB, Bouwstra H, van der Wouden JC, Hertogh CMPM, Wattel EM, Roorda LD, Terwee CB. Development of a Patient-Reported Outcomes Measurement Information System (PROMIS) short form for measuring physical function in geriatric rehabilitation patients. Qual Life Res. 2020 Sep;29(9):2563-2572.

31. Vermunt NPCA, Harmsen M, Westert GP, Olde Rikkert MGM, Faber MJ. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. BMC Geriatr. 2017 Jul 31;17(1):167.

32. Laver KE, Schoene D, Crotty M, George S, Lannin NA, Sherrington C. Telerehabilitation services for stroke. Cochrane Database Syst Rev. 2013 Dec 16;2013(12):CD010255.

33. Chen J, Jin W, Dong WS, Jin Y, Qiao FL, Zhou YF, Ren CC. Effects of Home-based Telesupervising Rehabilitation on Physical Function for Stroke Survivors with Hemiplegia: A Randomized Controlled Trial. Am J Phys Med Rehabil. 2017 Mar;96(3):152-160.

34. Sarfo FS, Ulasavets U, Opare-Sem OK, Ovbiagele B. Tele-Rehabilitation after Stroke: An Updated Systematic Review of the Literature. J Stroke Cerebrovasc Dis. 2018 Sep;27(9):2306-2318.

35. Laver KE, Adey-Wakeling Z, Crotty M, Lannin NA, George S, Sherrington C. Telerehabilitation services for stroke. Cochrane Database Syst Rev. 2020 Jan 31;1(1):CD010255.

36. Boots LM, de Vugt ME, Kempen GI, Verhey FR. Effectiveness of a Blended Care Self-Management Program for Caregivers of People With Early-Stage Dementia (Partner in Balance): Randomized Controlled Trial. J Med Internet Res. 2018 Jul 13;20(7):e10017.

37. Wolf TJ, Baum CM, Lee D, Hammel J. The Development of the Improving Participation after Stroke Self-Management Program (IPASS): An Exploratory Randomized Clinical Study. Top Stroke Rehabil. 2016 Aug;23(4):284-92.

38. Faux SG, Arora P, Shiner CT, Thompson-Butel AG, Klein LA. Rehabilitation and education are underutilized for mild stroke and TIA sufferers. Disabil Rehabil. 2018 Jun;40(12):1480-1484.

39. Bernocchi P, Vanoglio F, Baratti D, Morini R, Rocchi S, Luisa A, Scalvini S. Home-based telesurveillance and rehabilitation after stroke: a real-life study. Top Stroke Rehabil. 2016 Apr;23(2):106-15.

40. Doraiswamy S, Abraham A, Mamtani R, Cheema S. Use of Telehealth During the COVID-19 Pandemic: Scoping Review. J Med Internet Res. 2020 Dec 1;22(12):e24087.

41. Behandelkaders Geriatrische Revalidatie, Verenso 2010.

42. Mutai H, Furukawa T, Araki K, Misawa K, Hanihara T. Factors associated with functional recovery and home discharge in stroke patients admitted to a convalescent rehabilitation ward. Geriatr Gerontol Int. 2012 Apr;12(2):215-22.

43. Lutz BJ, Young ME, Creasy KR, Martz C, Eisenbrandt L, Brunny JN, Cook C. Improving Stroke Caregiver Readiness for Transition From Inpatient Rehabilitation to Home. Gerontologist. 2017 Oct 1;57(5): 880-889.

44. Dutrieux RD, van Eijk M, van Mierlo ML, van Heugten CM, Visser-Meily JM, Achterberg WP. Discharge home after acute stroke: Differences between older and younger patients. J Rehabil Med. 2016 Jan;48(1):14-8.

45. Hariton E, Locascio JJ. Randomised controlled trials - the gold standard for effectiveness research: Study design: randomised controlled trials. BJOG. 2018 Dec;125(13):1716.

46. Corrado AM, Benjamin-Thomas TE, McGrath C, Hand C, Laliberte Rudman D. Participatory Action Research With Older Adults: A Critical Interpretive Synthesis. Gerontologist. 2020 Jul 15;60(5):e413-e427.

47. Vallenga D, Grypdonck MH, Hoogwerf LJ, Tan FI. Action research: what, why and how? Acta Neurol Belg. 2009 Jun;109(2):81-90.

48. Richtlijn Beroerte NHG 2018

49. Satink T, Cup EH, de Swart BJ, Nijhuis-van der Sanden MW. Self-management: challenges for allied healthcare professionals in stroke rehabilitation--a focus group study. Disabil Rehabil. 2015;37(19):1745-52.

50. Plant SE, Tyson SF, Kirk S, Parsons J. What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries? A systematic review and meta-synthesis. Clin Rehabil. 2016 Sep;30(9):921-30.

51. Rasmussen RS, Østergaard A, Kjær P, Skerris A, Skou C, Christoffersen J, Seest LS, Poulsen MB, Rønholt F, Overgaard K. Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: a randomised controlled trial. Clin Rehabil. 2016 Mar;30(3):225-36.

52. Op weg naar beter. De ontwikkelagenda voor een overkoepelende kwaliteitsstandaard voor de kortdurende herstelgerichte zorg. Consortium Geriatrische revalidatie. Januari 2021.

7

53. Grund S, Gordon AL, van Balen R, Bachmann S, Cherubini A, Landi F, Stuck AE, Becker C, Achterberg WP, Bauer JM, Schols JMGA. European consensus on core principles and future priorities for geriatric rehabilitation: consensus statement. Eur Geriatr Med. 2020 Apr;11(2):233-238.

54. Grund S, van Wijngaarden JP, Gordon AL, Schols JMGA, Bauer JM. EuGMS survey on structures of geriatric rehabilitation across Europe. Eur Geriatr Med. 2020 Apr;11(2):217-232.

55. Wray F, Clarke D, Forster A. Post-stroke self-management interventions: a systematic review of effectiveness and investigation of the inclusion of stroke survivors with aphasia. Disabil Rehabil. 2018 Jun;40(11):1237-1251.

56. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M; Medical Research Council Guidance. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ. 2008 Sep 29;337:a1655.

57. Wensing M, Grol R, Grimshaw J. Improving Patient Care. The implementation of change in health care. Wiley Blackwell. 3rd edition 2020.

Impact

This chapter addresses the contribution of this dissertation to society and science. The societal impact, the efforts for further dissemination of the results, and suggestions for future research are described below.

Society

Stroke is one of the major causes of loss of independence, decreased quality of life and mortality among the older population[1,2]. Each year, about 40,000 people in the Netherlands, of which 56 % are 65 years or older, are affected by stroke and associated functional impairments[3,4]. After admission to a hospital, about one third of older stroke patients is referred to geriatric rehabilitation for rehabilitation[5-8]. After discharge from geriatric rehabilitation almost half of these older stroke patients still have persisting impairments in daily functioning due to stroke related problems such as paresis, cognitive deficits, fatigue, behaviour problems and depression[9-13]. These problems may result in a decrease of the patient's functional level, increased social isolation and/or increased care dependency, which may even result in permanent admission to a nursing home[9-13]. Stroke and its remaining consequences may also have a negative impact on the care burden and quality of life of informal caregivers of patients[14,15]. Therefore, adequate and supporting stroke aftercare is not only a relevant issue for older stroke patients, but also for their informal caregivers[16].

To improve stroke aftercare, a new rehabilitation programme was developed in collaboration with the relevant actors in stroke care, including patients and their informal caregivers, to improve aftercare for stroke patients and informal caregivers after discharge from rehabilitation. The studies reported in this dissertation provide insight into the development, effectiveness and feasibility of this newly developed geriatric rehabilitation programme.

The systematic review which was conducted in this study (chapter 2) presents all available interventions for stroke aftercare after discharge from rehabilitation. The review emphasises the scarcity of available evidence and underlines the importance of studying stroke rehabilitation and aftercare within the geriatric rehabilitation care setting. The findings of this review were published in an open access journal, freely accessible for stroke professionals and policy makers[17.].

The findings of the review are also relevant for stroke guideline development to provide information to stroke professionals working in rehabilitation and community health care.

In order to predict a successful discharge to the former living situation it is important to have insight into prognostic factors of stroke patients for being discharged to their former living situation. Chapter 3 of the dissertation contains a study on predicting factors for home discharge after inpatient rehabilitation in the geriatric population[18]. Findings were published in an open access journal. Results of this study may help stroke rehabilitation teams in predicting discharge location. The study revealed that particularly a higher level of independence in activities of daily living at admission is significantly associated with home discharge. In daily practice, this information can be used in the selection of patients for geriatric rehabilitation. It remains important to gain additional insight in other factors that might predict home discharge among frail older stroke patients after geriatric rehabilitation. Future research should focus on factors such as the pre-existing level of frailty, factors related to social support, the availability of family and/or other informal caregivers and motivational factors.

The protocol of the MAESTRO-study (chapter 4), gives a description of the integrated geriatric rehabilitation programme for older people with stroke and the design of the multicentre randomized controlled trial [19]. To improve feasibility and acceptance, the programme was developed in close collaboration with stroke professionals working in rehabilitation care services and community care. Furthermore, members of the Dutch Stroke Patient Association and the Informal Caregivers Association were involved as a member of the advisory board during the study.

The study provides an example of how relevant stakeholders can be intensively involved in rehabilitation research. Stimulating participation of all relevant stakeholders and especially of patients and informal caregivers should become the standard in designing, executing and evaluating scientific studies in the domain of geriatric rehabilitation.

The results of the effect and process evaluation of the newly developed integrated programme are described in chapter 5 and 6[20,21]. The most important goal of the programme was to improve the activity level of patients and to reduce the care burden and increase the quality of life of informal caregivers. The programme was evaluated in 8 regions of the Netherlands on feasibility and effectiveness. Although the programme showed no significant effects on the primary outcome measure, the programme did show its potential value by revealing favourable effects on social participation and quality of life of stroke patients. Furthermore, the programme proved to be effective in decreasing the care burden of informal caregivers, which is an important result because informal caregivers play an essential role in the care for stroke patients, especially after home discharge.

The results of the effect and process evaluation, which are both published in open access journals[20,21], can contribute to further improvement of the programme. Therefore, although the original programme needs further improvement, it may have favourable outcomes for both patients and caregivers.

Science

This dissertation is just one of few studies that focusses on improving stroke rehabilitation and aftercare for frail older stroke patients and their informal caregivers. The results of this research give insight in a possible rehabilitation programme for older stroke patients, which seems to have potential but needs further adaptations to increase effectiveness and feasibility. Therefore, there is a need for additional high-quality studies that assess the (cost-)effectiveness of different types of multidisciplinary stroke care including aftercare in geriatric rehabilitation. Future research should be based on theoretical frameworks and previous findings in research, combined with practice based evidence, in order to increase the potential quality of stroke aftercare programmes. Thereby, future research should have specific attention for the implementation of complex interventions as evaluated in this thesis. The findings of our thesis can help to improve future studies and improve feasibility and related effects.

To contribute to the further development of stroke care in geriatric rehabilitation, the results of the studies described in this dissertation were integrated in the Dutch National Stroke Knowledge Network guideline of care in the chronic phase after a stroke (in Dutch: "Leidraad Uitbehandeld! Hoezo?")[22], which gives stroke professionals tools and advices on stroke after care management.

For health care professionals, developing evidence based treatment for stroke rehabilitation is a continuous process that begins with neurorehabilitation education[23-25]. The knowledge generated in this dissertation was integrated in lectures to students of the bachelor of physiotherapy programme at SOMT university of physiotherapy in Amersfoort and the geriatric physiotherapy programme of Avans+ university of applied science in Breda.

Further, results of the research were disseminated via presentations on national and international congresses such as the "Geriatriedagen" in Den Bosch, the Netherlands, the "Kennisnetwerk CVA NL" symposium in Utrecht, the Netherlands, the "Nationaal Programma Ouderenzorg" congress in Den Bosch, the Netherlands, and the 4th European Nursing Congress in Rotterdam, the Netherlands.

Additional scientific impact was generated in several ways. First of all, the results were spread through the scientific community via open access publications. The results were also disseminated through publications of the "Nationaal Programma Ouderenzorg" from The Netherlands Organisation for Health Research and Development (ZonMw).

Moreover, based on the expertise developed in this study, the researcher (TV) was invited to participate in the development of the Dutch Stroke guideline for Physical therapy (In Dutch: "KNGF-richtlijn Beroerte")[24], the Dutch patient selection instrument for stroke (In Dutch: "CVA-triage instrument"), and the Dutch guideline for care in the chronic phase of stroke (In Dutch: "Leidraad Uitbehandeld! Hoezo?")[22]. This provided additional opportunities to contribute to the improvement of geriatric rehabilitation of stroke patients.

As mentioned above the results of this dissertation may have an impact on society and science in several ways. The results not only represent an important base for further knowledge dissemination on stroke rehabilitation and aftercare, but they also give recommendations for further research focused on improving stroke rehabilitation for older patients with stroke as well.

References

1. Lindsay MP, Norrving B, Sacco RL, Brainin M, Hacke W, Martins S, Pandian J, Feigin V. World Stroke Organization (WSO): Global Stroke Fact Sheet 2019. Int J Stroke. 2019 Oct;14(8):806-817.
2. GBD 2016 Stroke Collaborators. Global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016.Lancet Neurol. 2019 May;18(5):439-458.
3. Nivel Zorgregistraties eerste lijn 2018.
4. Gommer AM, Poos MJJC. Beroerte: prevalentie, incidentie en sterfte naar leeftijd en geslacht. Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM; 2011.
5. Behandelkaders Geriatrische Revalidatie, Verenso 2017.
6. Heijnen RW, Evers SM, van der Weijden TD, Limburg M, Schols JM. The cost effectiveness of an early transition from hospital to nursing home for stroke patients: design of a comparative study. BMC Public Health. 2010 May 26;10:279.
7. Inventarisatie zorginhoud GRZ. Het net opgehaald na zes jaar GRZ in de Zorgverzekeringswet. Q-Consult zorg. Utrecht februari 2019.
8. Achterberg WP, Cameron ID, Bauer JM, Schols JM. Geriatric Rehabilitation-State of the Art and Future Priorities. J Am Med Dir Assoc. 2019 Apr;20(4):396-398.
9. Norlander A, Carlstedt E, Jönsson AC, Lexell EM, Ståhl A, Lindgren A, Iwarsson S. Long-Term Predictors of Social and Leisure Activity 10 Years after Stroke. PLoS One. 2016 Feb 22;11(2):e0149395.
10. Dworzynski K, Ritchie G, Playford ED. Stroke rehabilitation: long-term rehabilitation after stroke.Clin Med (Lond). 2015 Oct;15(5):461-4.

11. Bachmann S, Finger C, Huss A, Egger M, Stuck AE, Clough-Gorr KM. Inpatient rehabilitation specifically designed for geriatric patients: systematic review and meta-analysis of randomised controlled trials. BMJ. 2010 Apr 20;340:c1718.

12. van Rijsbergen MWA, Mark RE, Kop WJ, de Kort PLM, Sitskoorn MM. Psychological factors and subjective cognitive complaints after stroke: Beyond depression and anxiety. Neuropsychol Rehabil. 2019 Dec;29(10):1671-1684.

13. Lo Coco D, Lopez G, Corrao S. Cognitive impairment and stroke in elderly patients. Vasc Health Risk Manag. 2016 Mar 24;12:105-16.

14. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: evidence-based clinical practice guidelines. J Rehabil Med. 2006;38(3):153–158.

15. Luker J, Murray C, Lynch E, Bernhardsson S, Shannon M, Bernhardt J. Carers' Experiences, Needs,and Preferences During Inpatient Stroke Rehabilitation: A Systematic Review of Qualitative Studies. Arch Phys Med Rehabil. 2017 Sep;98(9):1852-1862.e13.

16. Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF: Therapy-based rehabilitation services for patients living at home more than one year after stroke. Cochrane Database Syst Rev 2008, 16(2):CD005952.

17. Fens M, Vluggen T, van Haastregt JC, Verbunt JA, Beusmans GH, van Heugten CM. Multidisciplinary care for stroke patients living in the community: a systematic review. J Rehabil Med. 2013;45(4): 321–30.

18. Vluggen TPMM, van Haastregt JCM, Tan FES, Kempen GIJM, Schols JMGA, Verbunt JA.

19. Factors associated with successful home discharge after inpatient rehabilitation in frail older stroke patients. BMC Geriatr. 2020 Jan 23;20(1):25.

20. Vluggen TP, Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012;12(1):164.

21. Vluggen TPMM, van Haastregt JCM, Tan FE, Verbunt JA, van Heugten CM, Schols JMGA. Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial. BMC Geriatr. 2021 Feb 23;21(1):134.

22. Vluggen TPMM, van Haastregt JCM, Verbunt JA, van Heugten CM, Schols JMGA. Feasibility of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients: a process evaluation. BMC Neurol. 2020 May 29;20(1):219.

23. Bollars S, van Erp J, Fens M, van Gorp E, van Hoppe J, Krikke T, de Meris J, Notz B, van der Ven A, Vluggen T, Benjaminsen S. Uitbehandeld! Hoezo? Een leidraad in het doolhof van zorg in de chronische fase na een CVA: Kennisnetwerk CVA Nederland; 2012.

24. NHG standaard Beroerte, Nederlands Huisartsen Genootschap, 2018. KNGF-Richtlijn Beroerte, Koninklijk Nederlands Genootschap voor Fysiotherapie, Amersfoort 2014.

25. Richtlijn herseninfarct en hersenbloeding, Nederlandse vereniging voor neurologie, Utrecht 2017.

26. Cambier D, Hobbelen H, de Vries N. Geriatrie in de fysiotherapie en kinesitherapie, Bohn Stafleu van Loghum, Houten 2022.

Summary

Stroke is one of the major causes of loss of independence, decreased quality of life and mortality among the older population. Each year almost 40,000 people in the Netherlands are affected by stroke and associated functional impairments. Because of the increasing population of frail older patients with acute or chronic comorbidities there is a high prevalence of residual problems in older patients after stroke rehabilitation. Therefore, there is a need for improved and specialised aftercare to prevent or postpone functional decline after discharge and potentially avoidable permanent admissions to long term care facilities. As a response to the need for adequate and continued follow-up care after inpatient geriatric rehabilitation, in 2010, Maastricht University in collaboration with eight geriatric rehabilitation units, and primary care professionals, has developed an integrated rehabilitation programme (MAESTRO: Multidisciplinary Aftercare for Elderly persons with STROke study). This programme aims to provide adequate aftercare for older stroke patients and their informal caregivers, who receive inpatient rehabilitation and are discharged home. This dissertation describes the development, implementation and evaluation of this integrated rehabilitation programme.

The studies presented in this dissertation have four main objectives. The first objective is to develop an integrated rehabilitation programme based on evidence from literature and in collaboration with stroke professionals in the field. The second objective is to identify which factors were associated with home discharge after inpatient rehabilitation among frail and multimorbid older stroke patients. The third objective is to evaluate the effects of the integrated rehabilitation programme on the level of daily activity, functional independence, perceived quality of life and social participation in older stroke patients as compared with usual stroke care and additionally on the perceived care burden and quality of life of the informal caregivers. The fourth objective is to gain insight into the feasibility of the programme based on performance according to protocol, participation and opinions of patients, informal caregivers and stroke professionals.

In Chapter 1, the general introduction, the impact of stroke on the geriatric population and the related challenges in stroke care in general and specifically in geriatric stroke rehabilitation in the Netherlands are described. In addition, we report on the relevance and importance of preventing or postponing functional decline after discharge as well as potentially avoidable permanent admissions to long term care facilities. Furthermore, we describe the need to improve geriatric stroke rehabilitation by developing an integrated rehabilitation programme including adequate aftercare. Subsequently, the development process and content of this programme are presented. Finally, the objectives of the study and the outline of the dissertation are described.

In Chapter 2, a systematic literature review is presented, which provides insight in the effectiveness of multidisciplinary care for stroke patients living in the community and to identify elements to be used for development of the integrated geriatric rehabilitation programme. In this review, published in 2013 we included fourteen studies out of the 1425 screened titles and abstracts, describing aftercare programmes for stroke patients. Of these fourteen studies, twelve were conducted directly after discharge from the hospital, one in the community (≥ eighteen months post-stroke), and one after discharge from a rehabilitation facility. Four main types of interventions could be identified: 1) assessment (n=2); 2) assessment combined with follow-up care (n=8); 3) rehabilitation (n=3) and 4) education (n=1). The first type of intervention (assessment) consisted of a single visit at home or at a clinic to prevent a negative course of events. The second type of intervention (assessment combined with follow up care) consisted of an assessment with follow-up visits or rehabilitation care to improve coping and quality of life of stroke patients. The third type of intervention (rehabilitation) aimed to improve functional outcome and skills of stroke patients in their own living situation. The fourth type of intervention (education) aimed to stimulate social contacts and active recreation of stroke patients.

The review showed that two interventions (assessment combined with follow-up visits and rehabilitation) have a favourable effect on quality of life. Furthermore, multidisciplinary home-based interventions showed favourable effects on daily activities. However, the fourteen studies differed considerably in methodological quality. Therefore, we concluded there was limited evidence for the effectiveness of multidisciplinary care programmes for community living stroke patients after being discharged home and this indicated the need for further research.

In Chapter 3, we present the results of a study in which we identified factors associated with successful home discharge after inpatient rehabilitation in frail older stroke patients. To identify these relevant factors, first the literature was checked on factors among the general population of stroke patients and this revealed five important categories of factors measured at admission to rehabilitation which are significantly correlated to home discharge: 1) demographic characteristics, 2) social and environmental characteristics, 3) stroke related health status, 4) general health status, 5) functional status. To identify whether these potentially relevant factors, were also associated with home discharge after inpatient rehabilitation in our population of frail, older stroke patients, a longitudinal cohort study was performed based on data from the MAESTRO-study (see chapter 4 to 6). Only data from the usual care group was used for analysis to avoid a potential intervention effect in the data since the MAESTRO- study was set up as a randomized controlled trial. As a result, the study sample for this study consisted of 92 persons admitted to an intermediate care facility for geriatric rehabilitation. Inclusion criteria of patients were:

1) age 65 years of older, 2) living independently in the community before stroke, and 3) being admitted to one of eight intermediate care facilities for geriatric rehabilitation in the Netherlands under the initial prognosis that they would be able to return to their previous living situation within six months after the start of the geriatric rehabilitation. Results showed that from the sixteen factors (age; sex; household situation before admission; stroke history; cognitive disability; neglect; apraxia; dysphagia; urinary and bowel incontinence; emotional problems; cardiovascular disorders; diabetes mellitus; multimorbidity; sitting balance; daily activity level; and independence in activities of daily living) that were selected as a potential predictor for home discharge only *a higher level of independence in activities of daily living* was significantly related to returning to the previous living situation within 6 months. For future research, it is important to gain more insight in other factors that might predict home discharge among frail older stroke patients after geriatric rehabilitation, such as the level of frailty, factors related to social support, the availability of family and/or caregivers, and motivational factors.

In Chapter 4, we present the protocol of the MAESTRO-study, which includes a description of the integrated geriatric rehabilitation programme for frail older people with stroke and the design of the multicentre randomized controlled trial evaluating effects of the programme and the process evaluation assessing the feasibility of the programme. The programme was developed in collaboration with stroke professionals, and representatives of stroke patients and informal caregivers and consists of three care modules: 1) neurorehabilitation treatment for older stroke patients; 2) empowerment training for patient and informal caregiver; and 3) stroke education for patient and informal caregiver. Module 1 (neurorehabilitation treatment) was conducted during the inpatient phase and focused on (re)learning abilities needed for individual stroke patients to function as independently as possible in their home environment. During inpatient rehabilitation, an occupational therapist and physical therapist also trained the patients during guided home visits in their home environment, to optimise recovery, increase independence and to check whether the patients' home needed any modification before discharge. Module 2 (empowerment training), started during discharge to the home environment and focused on learning to cope with residual impairments as a result of stroke. Furthermore, patients and informal caregivers were trained by a transmural stroke coordinator in coping strategies and empowerment techniques based on self-management strategies. The transmural stroke coordinator joined the multidisciplinary stroke team and facilitated the transition of inpatient nursing home rehabilitation care to community care by supporting the collaboration between the multidisciplinary stroke team of the geriatric rehabilitation facility and the community health services, including community nurses, allied health professionals and the general practitioner. After discharge, the coordinator conducted home visits, supports the general practitioner by organising

multidisciplinary stroke team meetings and guided the patient and informal caregiver in learning to apply self-management techniques.

Module 3 (stroke education), was offered after discharge from inpatient rehabilitation and consisted of four educational meetings for patients and informal caregivers with the focus on psychological and emotional consequences of stroke, perceived problems in living independently and returning to society and the new role of the informal caregivers. The education course was organised in cooperation with the Dutch Stroke Patient Association and Informal Caregivers Association.

The total programme had a duration varying from two to six months, depending on the individual problems of the patient and informal caregiver. The usual care group received usual geriatric rehabilitation and community care.

Chapter 5 provides insight into the effects of the integrated rehabilitation programme described in chapter 4 on daily activity (primary outcome), and functional independence, perceived quality of life and social participation (secondary outcomes). In addition, the effects of the programme on the perceived care burden, objective care burden, and quality of life of the informal caregivers are presented. We conducted a multicentre randomized controlled trial in eight geriatric rehabilitation stroke units and their collaborating partners in primary care. The study population involved stroke patients (aged 65 or over) and their informal caregivers, living in the community before admission to geriatric rehabilitation, and expected to be able to return home after discharge from geriatric rehabilitation. In total 190 patients (mean age: 78.9 years) and 172 informal caregivers (mean age: 60.8 years) were included. Of these 190 patients 99 patients were randomised to the intervention group and 91 patients to the usual care group. Of the 172 informal caregivers 90 were randomised to the intervention group and 82 to the usual care group.

The programme consisted of three modules which are described above (see chapter 4). For patients, daily activity (FAI) was assessed as primary outcome parameter and functional dependence (Katz-15), perceived quality of life (SSQoL) and social participation (IPA) as secondary outcomes. Additionally, among informal caregivers perceived care burden (self-rated burden VAS), objective care burden (Erasmus iBMG), and quality of life (CarerQol), were assessed as secondary outcomes. Data for the effect evaluation was collected by face-to-face interviews among patients and self-reported questionnaires among informal caregivers. Research assistants conducted the interviews in the geriatric rehabilitation unit and at the patient's home and provided the self-administered questionnaires to caregivers at baseline, after six months and after twelve months. The ultimate results of the two-level multilevel analysis on patient level showed that the intervention had no effect on the primary outcome parameter daily activity as measured with the FAI. The analyses showed a significant favourable effect for the intervention on

the subscale "Autonomy outdoors" of the IPA scale. Autonomy outdoors are activities such as social contacts, leisure activities, and to get around outdoors when and where you want. All other secondary outcome measures showed no significant effects. Furthermore, regarding the informal caregivers the intervention had a significant favourable effect on caregiver burden (assessed with the Self-Rated Burden vas scale), but no effects on the other outcome measures were observed.

Based on these results, on outdoor autonomy and caregiver burden, the programme might be considered promising in providing adequate aftercare. However, adaptation of the programme is recommended to increase its feasibility (see chapter 6) and to improve its favourable effects for patients and informal caregivers.

Chapter 6 presents the results of the process evaluation which aimed to gain insight in the feasibility of the programme by: 1) evaluating to what extent the integrated multidisciplinary rehabilitation programme was performed according to protocol; 2) evaluating the participation of the patients in the programme; and 3) assessing the opinion of patients, informal caregivers and care professionals on the programme. Based on a methodological approach using multi-methods process data by means of interviews, questionnaires, and registration forms were gathered among 97 older stroke patients, 89 informal caregivers, and 103 care professionals involved in the programme. The study revealed that the program was conducted only partly according to protocol and that the feasibility of the new rehabilitation programme therefore needs further attention. Because of the persisting cognitive deficits and specific care needs in our target population some methods such as goal attainment scaling, empowerment training based on self-management and stroke education seemed not always feasible in its current form. To optimize feasibility, these elements need to be tailored more optimally to our target population of frail older stroke patients. We expect that increasing the feasibility of the programme could also further increase its effectiveness. In addition, applying an action research method could be a useful way to tailoring the programme more optimally to the care setting, patients, and care professionals involved.

The final chapter of this dissertation (Chapter 7, general discussion) summarises, discusses and reflects on the main findings and implications of the of the studies described in this dissertation, together with its methodological strengths and limitations. It is concluded that the programme might be promising in providing adequate (after)care for frail older stroke patients, although adaptation of the programme is recommended to increase its feasibility and improve its effects on improving rehabilitation outcome.

Samenvatting

Een beroerte is een van de belangrijkste oorzaken van verlies van zelfstandig functione-ren, verminderde kwaliteit van leven en sterfte onder de oudere bevolking. In Nederland worden jaarlijks bijna 40.000 mensen getroffen door een beroerte en de hiermee ge-paard gaande functionele beperkingen.

Vanwege het feit dat de populatie van kwetsbare oudere patiënten met een beroerte en comorbiditeit mede door de vergrijzing verder zal toenemen de komende decennia, is het van groot belang te zorgen voor adequate revalidatie én gespecialiseerde nazorg om functionele achteruitgang na ontslag te beperken en permanente opname in een instelling zo lang als mogelijk uit te stellen. Als reactie op de behoefte aan adequate na-zorg na intramurale geriatrische revalidatie, ging in 2010 de Universiteit Maastricht een samenwerking aan met acht afdelingen voor geriatrische revalidatie alsmede zorgpro-fessionals in de eerstelijn die samen een geïntegreerd revalidatieprogramma (MAESTRO: Multidisciplinary Aftercare for Elderly persons with STROke study) ontwikkelden voor oudere patiënten met een beroerte. Het nieuwe programma beoogde naast intramurale geriatrische revalidatie ook nazorg te bieden aan oudere patiënten met een beroerte en hun mantelzorgers.

Dit proefschrift beschrijft de ontwikkeling, uitvoering en evaluatie van dit nieuwe integra-le revalidatieprogramma. Het onderzoek, had vier doelstellingen. De eerste doelstelling was het ontwikkelen van dit geïntegreerd revalidatieprogramma op basis van gegevens uit de literatuur en in samenwerking met zorgprofessionals in het werkveld. De tweede doelstelling was factoren te identificeren die geassocieerd zijn met ontslag naar huis na intramurale revalidatie. Het derde doel was het evalueren van de effecten van het ontwikkelde geïntegreerde revalidatieprogramma op het niveau van dagelijkse activi-teiten, functionele zelfstandigheid, ervaren kwaliteit van leven en sociale participatie bij oudere patiënten met een beroerte in vergelijking met gebruikelijke revalidatiezorg bij deze doelgroep. Tevens werd het effect op de ervaren zorglast en kwaliteit van leven van de betrokken mantelzorgers onderzocht. De vierde doelstelling was inzicht te krijgen in hoeverre het programma was uitgevoerd volgens protocol, alsook wat de mate van participatie en de meningen van patiënten, mantelzorgers en zorgprofessionals over het programma waren.

In hoofdstuk 1, de algemene inleiding, worden de impact van een beroerte op de geria-trische populatie en de uitdagingen in de revalidatiezorg voor ouderen met een beroer-te in Nederland beschreven. Daarnaast wordt gerapporteerd over de relevantie en het belang van goede nazorg met als doel functieverlies na ontslag te voorkomen en tevens ook te zorgen dat een eventuele permanente opname in een instelling voor langdurige zorg zo lang als mogelijk wordt uitgesteld. Verder wordt de noodzaak beschreven om

de revalidatie na een beroerte te verbeteren door een geïntegreerd revalidatieprogramma te ontwikkelen voor de intramurale geriatrische revalidatie en nazorg. Vervolgens worden het ontwikkelingsproces en de inhoud van het revalidatieprogramma gepresenteerd. Dit hoofdstuk eindigt met de doelstellingen van het evaluatieonderzoek en de verdere opzet van het proefschrift.

In hoofdstuk 2 wordt een systematische review beschreven die inzicht geeft in de bestaande literatuur over de effectiviteit van multidisciplinaire zorg voor oudere patiënten met een beroerte die in de thuissituatie wonen. Verder beschrijft deze review informatie over belangrijke elementen die gebruikt kunnen worden voor de ontwikkeling van een nieuw geïntegreerde geriatrische revalidatieprogramma. In deze review, gepubliceerd in 2013, werden veertien relevante studies uit de 1425 gescreende titels en abstracts geselecteerd die nazorgprogramma's hebben geëvalueerd bij oudere patiënten met een beroerte.

Van de veertien geselecteerde onderzoeken werden er twaalf direct uitgevoerd na ontslag uit het ziekenhuis, één in de thuissituatie (≥ achttien maanden na een beroerte) en één na ontslag uit de revalidatie. Binnen de geselecteerde onderzoeken konden vier soorten interventies worden onderscheiden: 1) alleen een assessment (n=2); 2) assessment gecombineerd met nazorg (n=8); 3) intramurale revalidatie (n=3) en 4) educatie (n=1). Het eerste type interventie bestond uit een eenmalig assessment tijdens een preventief bezoek aan huis of binnen een zorginstelling. Het tweede type interventie bestond uit een assessment met vervolgbezoeken of revalidatiezorg, met als doel het verbeteren van de omgang met de gevolgen van een beroerte en om de kwaliteit van leven van patiënten met een beroerte te verbeteren. Het derde type interventie bestond uit intramurale revalidatie gericht op verbetering van het functioneren van mensen met een beroerte. Het vierde type interventie bestond uit educatie gericht op het delen van informatie over de onzichtbare gevolgen van een beroerte, het stimuleren van sociale contacten en sociale participatie van patiënten met een beroerte.

Uit de systematische review bleek dat twee interventies (assessment gecombineerd met nazorg en intramurale revalidatie) een gunstig effect hebben op de kwaliteit van leven van oudere patiënten met een beroerte. Verder lieten multidisciplinaire thuisinterventies gunstige effecten zien op het dagelijkse activiteitenniveau van patiënten met een beroerte. De veertien geselecteerde studies verschilden echter aanzienlijk in methodologische kwaliteit. Daarom was de conclusie van de review dat er beperkt bewijs was voor de effectiviteit van multidisciplinaire zorgprogramma's voor thuiswonende patiënten met een beroerte nadat ze naar huis zijn ontslagen. Deze conclusie gaf ook duidelijk

aan dat er behoefte was aan verder onderzoek naar multidisciplinaire zorgprogramma's voor deze doelgroep.

In hoofdstuk 3 presenteren we de resultaten van een onderzoek naar factoren die geassocieerd zijn met ontslag naar huis na intramurale revalidatie bij kwetsbare ouderen met een beroerte. Om deze potentiële voorspellende factoren te identificeren zijn er drie stappen uitgevoerd: Stap 1) In de literatuur is gezocht naar factoren die samen hangen met ontslag naar huis in de algemene populatie van patiënten met een beroerte; Stap 2) Indien de gevonden factoren ook waren gemeten binnen het MAESTRO-onderzoek (zie hoofdstuk 4 t/m 6) werden ze meegenomen in de analyse; Stap 3) Vervolgens werden de geselecteerde factoren onderverdeeld in vijf categorieën. Deze betroffen: 1) demografische kenmerken, 2) sociale en omgevingskenmerken, 3) beroerte gerelateerde gezondheidsstatus, 4) algemene gezondheidsstatus, en 5) functionele status.

Alleen gegevens van de controlegroep van de MAESTRO studie werden gebruikt voor de analyse. Deze groep bestond uit 92 patiënten die opgenomen waren in een instelling voor geriatrische revalidatie.

Uit de resultaten bleek dat zestien factoren (leeftijd; geslacht; woonsituatie voor opname; ziektegeschiedenis; cognitieve beperking; neglect; apraxie; dysfagie; incontinentie; emotionele problemen; cardiovasculaire stoornissen; diabetes; multimorbiditeit; zitbalans; dagelijks activiteitenniveau; en zelfstandigheid binnen activiteiten van dagelijks leven) werden geselecteerd als potentiële voorspeller voor ontslag naar huis. Resultaten laten zien dat uiteindelijk alleen een hogere mate van zelfstandigheid in de activiteiten van het dagelijks leven bij opname was gerelateerd aan terugkeer naar de woonsituatie. Voor toekomstig onderzoek is het belangrijk om meer inzicht te krijgen in andere factoren die ontslag naar huis zouden kunnen voorspellen bij kwetsbare patiënten opgenomen voor geriatrische revalidatie. Mogelijk belangrijke factoren om in toekomstig onderzoek mee te nemen zijn de mate van kwetsbaarheid, beschikbaarheid van (sociale) ondersteuning door bijvoorbeeld familie of vrienden en mogelijke andere belangrijke factoren.

In hoofdstuk 4 presenteren we het protocol van de MAESTRO-studie, inclusief een beschrijving van het integrale geriatrische revalidatieprogramma voor kwetsbare ouderen met een beroerte. Tevens wordt ook het design beschreven van de multicenter, gerandomiseerde, gecontroleerde studie waarin de effecten en het proces van het programma werden onderzocht. Het integrale programma, ontwikkeld in samenwerking met zorgprofessionals en vertegenwoordigers van patiënten met een beroerte en hun mantelzorgers, bestaat uit drie zorgmodules: 1) intramurale neurorevalidatie tijdens

de klinische geriatrische revalidatie; 2) zelfmanagementtraining voor patiënten en mantelzorgers; en 3) educatie over beroerte voor patiënten en mantelzorgers. De eerste module (intramurale neurorevalidatie) werd uitgevoerd tijdens de intramurale fase en was gericht op het (her)leren van vaardigheden die nodig zijn voor individuele patiënten met een beroerte om weer zo zelfstandig mogelijk te functioneren na ontslag naar huis. Tijdens deze klinische revalidatiefase trainden een ergotherapeut en fysiotherapeut de patiënten eveneens tijdens bezoeken in de thuissituatie van de patiënt. Tevens werd er ook gecontroleerd op de eventuele noodzaak voor aanpassing van de woning voordat de patiënt kon terugkeren naar huis. De tweede module 2 (zelfmanagement), startte na ontslag naar huis en was gericht op het leren omgaan met resterende beperkingen als gevolg van een beroerte. De patiënten en mantelzorgers werden getraind door een transmurale zorgcoördinator in copingstrategieën en empowermenttechnieken op basis van zelfmanagement. De transmurale zorgcoördinator was onderdeel van het multidisciplinair revalidatieteam en werd ingezet om de overgang van intramurale revalidatie naar huis te verbeteren, en de samenwerking tussen het intra- en extramurale multidisciplinaire team goed te laten verlopen. Na ontslag werden er door de coördinator huisbezoeken afgelegd, ondersteunde de coördinator de huisarts bij het organiseren van het multidisciplinair teamoverleg in de eerste lijn en werden patiënt en mantelzorger verder begeleid bij het leren toepassen van zelfmanagementtechnieken. In module 3 (educatie over beroerte) werd educatie over beroerte aangeboden na ontslag uit de klinische revalidatie. De educatie bestond uit vier voorlichtingsbijeenkomsten voor patiënten en mantelzorgers met de focus op de psychologische en emotionele gevolgen van een beroerte, de ervaren problemen bij ontslag naar de thuissituatie en de nieuwe rol van de mantelzorgers. De educatie werd georganiseerd in samenwerking met de Nederlandse vereniging voor patiënten met een beroerte en het Steunpunt Mantelzorg. Het integrale revalidatieprogramma had een looptijd variërend van twee tot zes maanden, afhankelijk van de individuele problemen van patiënt en mantelzorger. De controlegroep kreeg de gebruikelijke geriatrische revalidatiezorg aangeboden.

In hoofdstuk 5 worden de effecten van het integrale revalidatieprogramma (hoofdstuk 4) beschreven   met als belangrijkste uitkomstmaat het dagelijks activiteitenniveau en als secundaire uitkomstmaten functionele onafhankelijkheid, kwaliteit van leven en sociale participatie. Tevens werd er gekeken naar de effecten op de ervaren zorglast, objectieve zorglast en de kwaliteit van leven van de mantelzorger. Een gerandomiseerde multicenter trial werd uitgevoerd in acht geriatrische revalidatie afdelingen en hun samenwerkingspartners in de eerstelijnszorg. De onderzoekspopulatie bestond uit patiënten met een beroerte van 65 jaar of ouder, die vóór opname nog thuis woonden en naar verwachting in staat waren om naar huis terug te keren na ontslag uit geriatrische revalidatie. Tevens werden ook de primaire mantelzorgers in het onderzoek

geïncludeerd. In totaal werden er 190 patiënten (gemiddelde leeftijd: 78,9 jaar) en 172 mantelzorgers (gemiddelde leeftijd: 60,8 jaar) geïncludeerd. Van de 190 geïncludeerde patiënten werden er 99 patiënten gerandomiseerd naar de interventiegroep en 91 patiënten naar de controlegroep. Van de 172 mantelzorgers werden er 90 gerandomiseerd naar de interventiegroep en 82 naar de controlegroep. Het integrale revalidatieprogramma bestond uit drie modules die hierboven zijn beschreven (zie hoofdstuk 4). Voor patiënten was dagelijkse activiteit (FAI) de primaire uitkomstmaat en functionele afhankelijkheid (Katz-15), ervaren kwaliteit van leven (SSQoL) en sociale participatie (IPA) de secundaire uitkomstmaten. Voor de mantelzorgers was de subjectieve zorglast (Self-Rated Burden VAS) de primaire uitkomstmaat en de objectieve zorgbelasting (Erasmus iBMG) en kwaliteit van leven (CarerQol) de secundaire uitkomstmaten. De data voor de effectevaluatie werden verzameld via interviews met patiënten en via vragenlijsten voor de mantelzorgers. Onderzoeksassistenten voerden de interviews uit bij opname, na zes maanden en na twaalf maanden op de geriatrische revalidatieafdeling of bij de patiënt thuis. De resultaten lieten zien dat de interventie geen effect had op de primaire uitkomstmaat dagelijks activiteitenniveau. Uit de analyses bleek er echter wel een significant positief effect te zijn van de interventie op de subschaal "Autonomie buitenshuis" van de IPA. Autonomie buitenshuis betreft activiteiten zoals sociale contacten, vrijetijdsbesteding en het buiten kunnen zijn wanneer de patiënt dat wil. Alle andere secundaire uitkomstmaten lieten geen significante effecten zien. Mantelzorgers van deelnemers aan het nieuwe programma ervaarden minder belasting dan mantelzorgers die gebruikelijke zorg hadden ontvangen. Op andere meetinstrumenten werden er geen effecten gevonden. Op basis van deze resultaten lijkt het programma bij te kunnen dragen aan adequate zorg voor oudere patiënten met een beroerte en hun mantelzorgers. Wel worden er aanpassingen aanbevolen om de haalbaarheid te vergroten (zie hoofdstuk 6) en om de gunstige effecten voor patiënten en mantelzorgers te verbeteren.

Hoofdstuk 6 presenteert de resultaten van de procesevaluatie die tot doel had inzicht te krijgen in de uitvoerbaarheid van het programma door: 1) te evalueren in hoeverre het multidisciplinair integrale revalidatieprogramma werd uitgevoerd volgens protocol; 2) de deelname van de patiënten aan het programma te evalueren; en 3) te beoordelen wat het oordeel van patiënten, mantelzorgers en zorgprofessionals is over het programma. Hiervoor werden op verschillende manieren gegevens verzameld (interviews, vragenlijsten en registratieformulieren) onder 97 patiënten, 89 mantelzorgers en 103 zorgprofessionals. De procesevaluatie laat zien dat het programma slechts gedeeltelijk volgens protocol werd uitgevoerd en dat de uitvoerbaarheid van het nieuwe revalidatieprogramma zeker verder aandacht behoeft. Mogelijk vanwege de aanhoudende cognitieve stoornissen en specifieke zorgbehoeftes in onze doelgroep bleken sommige onderdelen, zoals het maken van SMART geformuleerde revalidatiedoelen, zelfmanage-

menttraining en educatie omtrent beroerte in de huidige vorm niet altijd goed uitvoerbaar. Om het programma te optimaliseren moeten deze elementen daarom nog beter worden afgestemd op de populatie kwetsbare oudere patiënten met een beroerte. Door middel van action research zou het programma in de toekomst mogelijk beter kunnen worden afgestemd op de zorgsetting, patiënten, naasten en zorgprofessionals.

Het laatste hoofdstuk van dit proefschrift (Hoofdstuk 7, algemene discussie) bespreekt en reflecteert op de belangrijkste bevindingen en implicaties van de beschreven studies in dit proefschrift, samen met de methodologisch sterke punten en beperkingen. Geconcludeerd wordt dat het geïntegreerde revalidatieprogramma dat in de beschreven studies is onderzocht, een beperkte positieve bijdrage kan leveren aan de (na)zorg voor oudere patiënten met een beroerte en hun mantelzorgers. Aanbevolen wordt om het programma beter af te stemmen op de doelgroep en setting, om daarmee de uitvoerbaarheid en effectiviteit van het programma te vergroten.

Publicatieoverzicht

Publicaties

Vluggen TP, van Haastregt JC, Verbunt JA, Keijsers EJ, Schols JM. Multidisciplinary transmural rehabilitation for older persons with a stroke: the design of a randomised controlled trial. BMC Neurol. 2012 Dec 31;12:164.

Fens M, Vluggen T, van Haastregt JC, Verbunt JA, Beusmans GH, van Heugten CM. Multidisciplinary care for stroke patients living in the community: a systematic review. J Rehabil Med. 2013 Apr;45(4):321-30.

Tom Vluggen, Manon Fens, Jolanda van Haastregt, Jeanine Verbunt, George Beusmans en Caroline van Heugten. De effecten van multidisciplinaire nazorg voor thuiswonende CVA-patiënten, een systematische review. Fysiotherapie en ouderenzorg vakblad NVFG, september 2013.

Vluggen TPMM, van Haastregt JCM, Tan FES, Kempen GIJM, Schols JMGA, Verbunt JA. Factors associated with successful home discharge after inpatient rehabilitation in frail older stroke patients. BMC Geriatr. 2020 Jan 23;20(1):25.

Vluggen TPMM, van Haastregt JCM, Verbunt JA, van Heugten CM, Schols JMGA. Feasibility of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients: a process evaluation. BMC Neurol. 2020 May 29;20(1):219.

Vluggen TPMM, van Haastregt JCM, Tan FE, Verbunt JA, van Heugten CM, Schols JMGA. Effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older persons with stroke: a multicentre randomised controlled trial. BMC Geriatr. 2021 Feb 23;21(1):134.

Boeken

Bollars S, van Erp J, Fens M, van Gorp E, van Hoppe J, Krikke T, de Meris J, Notz B, van der Ven A, Vluggen T, Benjaminsen S: Uitbehandeld! Hoezo?. 2012, Kennisnetwerk CVA Nederland: Een leidraad in het doolhof van zorg in de chronische fase na een CVA.

Vluggen TPMM, Hoofdstuk 10: CVA, Geriatrie in de fysiotherapie en kinesitherapie. Bohn Stafleu van Loghum 2017.

Vluggen TPMM, Neurologische aandoeningen - CVA, Geriatrie in de fysiotherapie en kinesitherapie. Bohn Stafleu van Loghum 2022.

Richtlijnen

Veerbeek JM, van Wegen EEH, van Peppen RPS, Hendriks HJM, Rietberg MB, van der Wees PH J, Heijblom K, Goos AAG, Hanssen WO, Harmeling – van der Wel BC, de Jong LD, Kamphuis JF, Noom MM, van der Schaft R, Smeets C, Vluggen TPMM, Vijsma DRB, Vollmar CM, Kwakkel G. KNGF-richtlijn Beroerte. Koninklijk Genootschap voor Fysiotherapie, Amersfoort 2014.

Presentaties

Vluggen T. Samen Sterk na een Beroerte. Het MAESTRO-project, Multidisciplinair (na) zorgprogramma voor ouderen met een CVA. Geriatriedagen. 9 februari 2012, Den Bosch

Vluggen T. Transmurale CVA-revalidatie. Het MAESTRO-project. Multidisciplinair (na) zorgprogramma voor ouderen met een CVA. Kennisnetwerk CVA NL, 13 maart 2013, Zeist

Vluggen T. Kick-off Geriatrisch Zorgnetwerk CVA. 23 mei 2013, Revalidatiecentrum Adelante, Hoensbroek

Vluggen T. Het MAESTRO-project. Transmuraal multidisciplinair CVA-revalidatiepro-gramma voor ouderen. NPO slotcongres, 12 november 2013, Den Bosch.

Vluggen T, Krikke T. Minisymposium "Uitbehandeld! Hoezo?" Verslag van een imple-mentatieproces. Werkgroep chronische fase. Symposium Kennisnetwerk CVA NL. 22 november 2013, Zeist

Vluggen T. Het MAESTRO-project Multidisciplinair (na)zorgprogramma voor ouderen met een CVA. Obstakels overwinnen. GERION 25 jarig jubileumcongres, 5 september 2014, VU Amsterdam

Tom Vluggen MSc, Jolanda van Haastregt PhD, Jeanine Verbunt MD, PhD, Jos Schols MD, PhD Multidisciplinary aftercare for elderly persons with stroke (MAESTRO). Preliminary results of a randomized controlled trial European Nursing Congress, October 6th 2016, Rotterdam, the Netherlands

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Curriculum Vitae

Tom Vluggen is geboren op 13 oktober 1981 in Heerlen. Na afronding van de HAVO ging hij in 2001 aan de Zuyd Hogeschool in Heerlen fysiotherapie studeren waar hij in 2005 zijn diploma behaalde. Na afronding van de opleiding fysiotherapie is hij begonnen als fysiotherapeut binnen de ouderenzorgstichting Envida in Maastricht. In 2005 begon hij aansluitend aan de opleiding klinische gezondheidswetenschappen aan de Universiteit Utrecht waar hij in 2008 afstudeerde in de specialisatie fysiotherapiewetenschap. Door zijn passie voor fysiotherapie en ouderenzorg begint hij in 2017 te bouwen aan zijn eigen paramedische multidisciplinaire zorgpraktijk Dignita en start hij samen met een vriend en collega in 2020 de ouderengeneeskundepraktijk Parkstad op. Met beiden praktijk is hij in de Limburge zorg actief binnen zowel de 1e lijn, geriatrische revalidatie als chronische ouderenzorg. Naast zijn werk als fysiotherapeut en leidinggevende van een multidisciplinair zorgteam begon hij in 2010 aan zijn Phd-traject "Towards improved multidisciplinary stroke care for older people" aan de Universiteit Maastricht onder supervisie van Prof. Dr. Jos Schols, Prof. Dr. Jeanine Verbunt en Dr. Jolanda van Haastregt.