

MOVEMENT BEHAVIOR IN PEOPLE WITH A FIRST-EVER STROKE

THE RISE COHORT STUDY



UMC Utrecht Brain Center

RODERICK WONDERGEM

The RISE cohort study

**Movement behavior in people
with a first-ever stroke**

Roderick Wondergem

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Utrecht University, Utrecht, The Netherlands

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Movement behavior in people with a first-ever stroke

The RISE cohort study

Beweggedrag van mensen na een eerste beroerte

Het RISE cohort onderzoek

(met samenvatting in het Nederlands)

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Roderick Wondergem

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te Mariekerke

Promotoren: Prof. Dr. C. Veenhof
Prof. Dr. J.M.A. Visser-Meily
Prof. Dr. E.J.M. Wouters

Copromotor: Dr. M.F. Pisters

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“If we could give
every individual the right amount of nourishment and exercise,
not too little and not too much, we would have found
the safest way to health.”

Hippocrates

Voor mijn Ouders en Mijntje

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CHAPTER 1



GENERAL INTRODUCTION

The present thesis describes the results of the RISE (Reducing sedentary behavior, Identification of people at risk, in people with Stroke, Effectiveness in daily living) cohort study (figure I).



Figure I. RISE-study

Stroke

Stroke is a rapidly developing condition with clinical signs of focal (or global) disturbance of cerebral function. It can last more than 24 hours and lead to death with no apparent cause other than that of vascular origin¹. Stroke is one of the leading causes of mortality in the world² and the second most common cause of death in Europe³. It is one of the five leading causes of disability-adjusted life-years⁴ and in Europe, the leading cause of long-term disability⁵. The annual cost in Europe due to stroke is estimated to be €27 billion of direct health care costs and an additional €16 billion for informal care⁶. Especially in the last decade, mortality rates have decreased in people with stroke², resulting in an increase in years lived with disability due to stroke⁷. Due to decreased mortality rates, improved acute care facilities, and treatments such as thrombectomy and thrombolysis, outcomes after stroke are better than in the past⁸. As a result of improved outcomes, stroke has developed into a chronic condition forcing people to live with its (chronic) consequences.

Stroke care in the Netherlands is organized in so-called stroke services. Stroke services are a type of integrated care that has been established during the last decade. The aim of stroke services is to improve health outcomes and processes of care by connecting the acute, rehabilitation, and chronic phases of stroke care^{9,10}. In a typical Dutch stroke service, the hospital, rehabilitation center, geriatric rehabilitation center, nursing home, and primary care are represented. The majority of the stroke population in the Netherlands is discharged to the home setting after treatment in the hospital. Considering the improvements in acute treatment, more people will be discharged to the home setting in the future. Despite improvements in acute treatment, people with a stroke must still live with the long-term consequences^{11,12}. These are diverse and not only physical but also cognitive, psychological, and psychosocial¹³. Over fifty percent of people with stroke experience restrictions in activities of daily living (ADL), physical exercise, and outdoor activities. Additionally, people

with stroke experience relatively more restrictions on visiting friends, telephone contact, and leisure activities compared with their life before stroke¹⁴.

Secondary prevention

Mortality rates in people with a first stroke are high. Approximately fifty percent of people with stroke die within five years¹⁵, almost a quarter of the population will experience a recurrent event¹⁶, and a substantial part of the population declines in ADL¹⁷. Recurrent events occur even in those who received excellent evidence-based care¹⁸. Unfortunately, rehabilitation outcomes after a second stroke, as well as physical and cognitive outcomes, are reduced¹⁹. Secondary prevention after the first-ever stroke is, therefore, of paramount interest. In particular, the estimated potential for reducing recurrent events is 80%⁶. Although standard medical interventions for secondary prevention are reimbursed in most European countries, lifestyle interventions are not²⁰. People with stroke returning home after acute care will receive regular checkups by general practitioners. Primary care plays an essential role in the care of people with stroke and their caregivers. Traditionally managed aspects are facilitating transfer to specialists and other health care professionals, supporting access to community services, providing training, identifying and addressing the health needs of caregivers, and reducing risk factors²¹. However, the feeling of abandonment that people with stroke experience after hospital discharge is not eliminated²².

Effective secondary prevention programs are needed in people with stroke. Lifestyle factors such as diet, current smoking, stress, central adiposity, and physical activity are important and modifiable risk factors before and after stroke²³. Unfortunately, lifestyle advice is only offered to 25% of patients in the Netherlands, even after the introduction of a protocol²⁴. Overall, within secondary prevention programs after stroke, physical activity has received limited attention^{25,26}. This results in limited awareness of the health risk of reduced physical activity and sedentary behavior in stroke survivors^{27,28}. If physical activity receives attention, the information provided encourages patients to be sufficiently physically active. However, it is known that only providing information is ineffective²⁹, and sustainable behavioral change interventions are needed to change behavior.

Recovery of physical functioning with stroke

Consequences after stroke are diverse. The consequences of stroke can be classified within the World Health Organization's International Classification of Functioning, Disability, and Health³⁰. This framework can be used to classify the effects of stroke in terms of pathology, functions, activities, participation, environmental factors, and personal factors. Reducing the consequences after stroke is the main goal during rehabilitation. The majority of the top 10 research priorities are related to the recovery of functions and activities³¹. Additionally, the recovery of functions and activities is crucial for social integration³². Hypothetical

recovery patterns of people with stroke have been developed and suggest that recovery of functions and activities (physical functioning) reaches a plateau six months after stroke onset (figure II)^{33,34}. However, stroke recovery is heterogeneous, and different courses regarding the recovery of physical functioning have been noted³⁵. After six months, some patients may improve while others remain stable, and a substantial part of the stroke population will decline in terms of ADL³³.

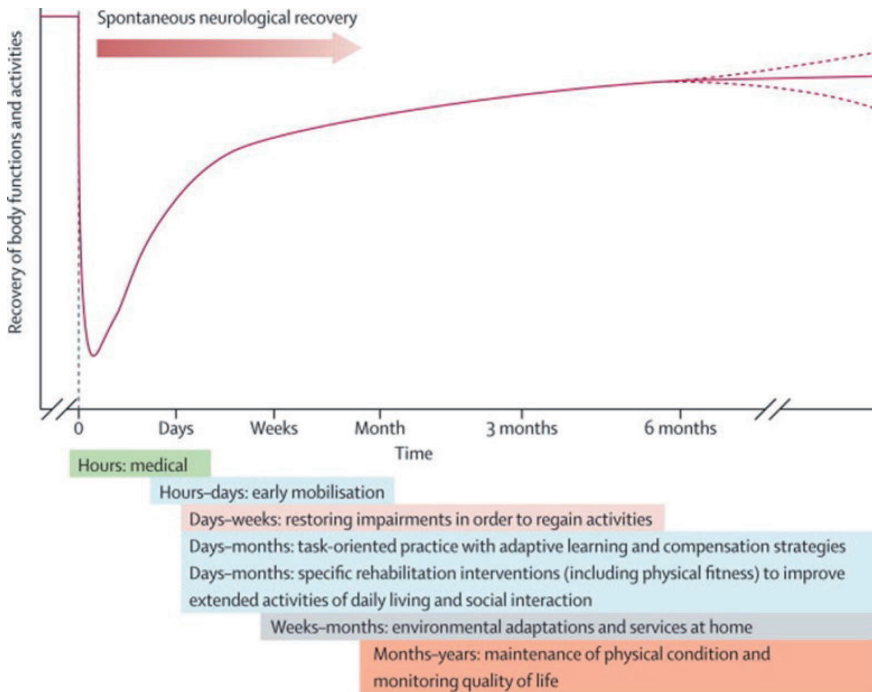


Figure II. Hypothetical model of recovery of body functions and activities³³.

Movement behavior

Sleeping behavior, sedentary behavior, and physical activity are part of the 24-hour cycle and can be seen as three different types of behavior (see figure III)³⁶. All three behaviors are independently associated with health outcomes³⁷. Sleeping behavior is defined as a spontaneous and reversible state of rest characterized by the inhabitation of voluntary muscles and sensory activity and by reduced consciousness, responsiveness to stimuli, and interactions with the environment³⁸. Sedentary behavior and levels of physical activity are movement behaviors during waking hours.

Physical activity can be performed at different energy levels and in different postures. Different energy levels are distinguished by metabolic equivalents (MET). The MET is a physiological

measure expressing the energy expenditure of physical activities against a reference of the metabolic cost or rest, for which the basal metabolic rate is 1.0 MET³⁹. One MET represents the individual use of 3.5 milliliters of oxygen per minute per kilogram of body mass. Light physical activity is defined as an energy expenditure between 1.5 and 3.0 MET, moderate physical activity between 3.0 and 6.0 MET, and vigorous physical activity above 6 MET.

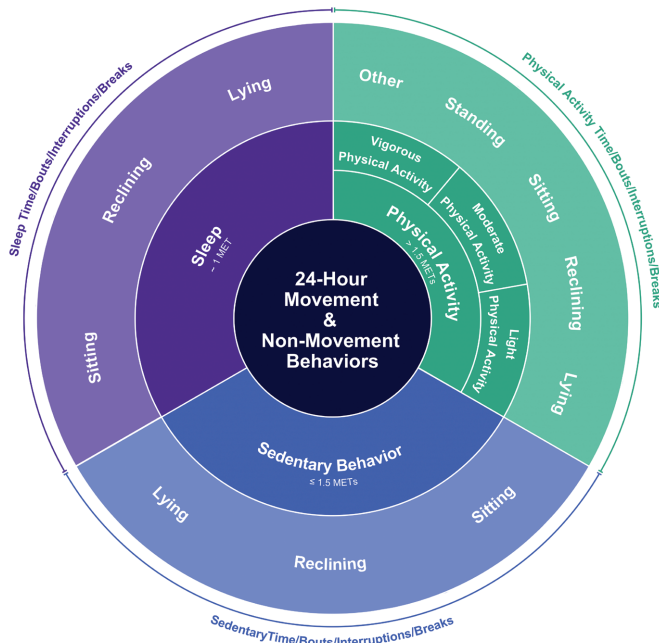


Figure III. Illustration of the final conceptual model of movement-based terminology arranged around a 24-hour period. The figure organizes the movements that take place throughout the day into two components: The inner ring represents the main behavior categories using energy expenditure. The outer ring provides general categories using posture. The proportion of space occupied by each behavior in this figure is not prescriptive of the time that should be spent on these behaviors each day (36).

Often, moderate and vigorous physical activity are taken together, resulting in moderate-to-vigorous intensity during physical activity (MVPA). Physical activity recommendations are based on MVPA. MVPA is often used to distinguish active people from inactive people. People who do at least 150 minutes MVPA per week are considered to be active, while others are considered inactive⁴⁰.

Sedentary behavior is defined as any waking behavior characterized by an energy expenditure of 1.5 or fewer MET while sitting, lying, or reclining posture⁴¹. This definition has been changed in recent years. In previous research, sleep time was included, and MET values were not mentioned in the definition. The inclusion of energy expenditure is essential because a lack

of muscle activity contributes to unfavorable health outcomes⁴². Adding waking behavior is essential because it excludes sleeping, which is a different behavior.

There is a difference between sedentary behavior and being physically inactive. Inactive people are those who are performing insufficient amounts of MVPA and are not necessarily sedentary. When an individual does not meet the recommendations for sufficient amounts of MVPA but spends little time in a sitting, reclining, or lying position, this person is inactive but not sedentary. Vice versa, an individual can be physically active, for example, cycling 30 minutes per day to their work, and spend the rest of the day in a sitting position working behind a desk. This individual is sedentary but sufficiently active.

Movement behavior and health consequences

The health benefits of physical activity have been established over decades⁴³. With an estimated portion of 6% of global deaths attributable to physical inactivity⁴³ and the power of physical activity to reduce the risk of cardiovascular disease, type 2 diabetes, and certain cancers⁴⁰, it has proven its importance. On the other hand, research and evidence suggesting the association between sedentary behavior and poor health are more recent⁴⁴. Recently, sedentary behavior has been related to all-cause mortality, cardiovascular diseases, type 2 diabetes, and metabolic syndrome⁴⁵. The adverse effect of sedentary behavior on health is an independent risk factor unrelated to the amount of physical activity^{46,47}. Not only is total sedentary time unfavorable, but mainly when sedentary behavior accumulates in prolonged periods^{48,49}, the consequences for health are more pronounced. These periods are called sedentary bouts. The underlying assumption of the importance of sedentary behavior is the lack of muscle activity in the muscle groups that contribute to weight bearing⁵⁰. Both sufficient amounts of physical activity *and* low amounts of sedentary behavior were found to be protective against limitations in ADL in the elderly^{51,52}.

Both sedentary behavior and amounts of physical activity are modifiable behaviors that can contribute to health benefits. Additionally, interrupting sedentary behavior could be another target to reduce health risks and prevent people from experiencing limitations in ADL. Recommendations about sufficient amounts of MVPA have already been integrated into guidelines all over the world⁴⁰. The recommendations about sufficient levels of physical activity are detailed, and there is a clear description of duration and intensity during the week. To date, only a few guidelines have included sedentary behavior in their recommendations^{53,54}. Contrary to PA, these recommendations lack a clear description of the maximum amount of sedentary behavior and how to interrupt prolonged sedentary behavior. In the recently published physical activity guidelines for Americans, the advice is given to reduce sedentary behavior, but further directions are not given.

Although the independent contributions of the single aspects of movement behavior to health are highlighted in research, these behaviors are not self-contained but cluster in patterns (e.g., high MVPA, high LPA, and low SB). Although a single aspect can have health benefits, this can be counteracted by another. For example, when an individual shows sufficient physical activity but is sedentary during the rest of the day, health risks are still high. Therefore, movement behavior should be investigated as a whole. Based on movement behavior patterns, interventions can be tailored.

Movement behavior in people with stroke

Studies suggest that the majority of people with stroke are inactive^{55,56}. Additionally, people with stroke seem to be sedentary for more than ten hours per day⁵⁷ and accumulate their total sedentary time in long prolonged sedentary bouts. However, the majority of the studies included mainly rehabilitation populations. Information about people who are discharged directly from the hospital to the home setting is lacking.

Cross-sectional associations with sedentary behavior were stroke severity and reduced functional independence. The amount of sedentary behavior in the first year after stroke does not change independently of the functional abilities of people with stroke.⁵⁵ Walking ability, balance, and degree of physical fitness are positively associated with higher levels of physical activity⁵⁷. The distribution of sedentary behavior and levels of physical activity (e.g., SB, LPA, and MVPA) and the accumulation (interrupting or prolonging sedentary behavior) of movement behavior during waking hours will guide future research. The composition of movement behavior differs per individual and reflects habitual behavior during waking hours. Insight into movement behavior patterns provides an important direction to personalize future interventions based on individual patterns.

Behavioral change to support sustainable movement

Current rehabilitation interventions focus on increasing physical activity by means of supervised training without paying attention to sedentary behavior⁵⁸. Although the benefits of physical activity with regard to risk management are known, it remains difficult for people with stroke to be and remain sufficiently physically active⁵⁹. Additionally, adherence to physical activity participation is known to decline over time⁶⁰, and participation in supervised physical activity training will not automatically result in an active and less sedentary lifestyle⁵⁹. In the literature, only two pilot studies were conducted targeting the reduction of sedentary behavior in people with stroke^{61,62}. The long-term effects of reducing sedentary behavior after stroke are currently unknown. However, to target future interventions, identification of the most typical movement behavior patterns in people with stroke is needed. This will enable health care professionals to offer individualized physical activity options tailored to individuals' needs to maximize health benefits.

Outline of the thesis

The general aims of this thesis were to investigate movement behavior in people who are discharged directly to the home setting, the course of movement behavior within the first two months after discharge to the home setting, and to identify unfavorable movement behavior pattern(s) in people with stroke. In addition, the consequences of movement behavior patterns regarding physical functioning are investigated. People with identified unfavorable movement behavior patterns might benefit from specific movement behavioral interventions to prevent the decline of physical functioning. Therefore, the first step, described in **Chapter 2**, was to provide the state of the art of recovery patterns for ADL after stroke. To be able to objectify a possible decline in activities in people with stroke, an assessment tool regarding the long-term follow-up of people with stroke is needed. Therefore, in **Chapter 3**, the concurrent validity and responsiveness of the Late-Life Function and Disability Index Computerized Adaptive test were investigated.

To identify movement behavior outcomes, the validity of the Activ8 accelerometer was investigated in **Chapter 4** since this accelerometer is comfortable to wear, can collect thirty days of measurements without charging, and is able to give real-time feedback.

Within **Chapter 5**, movement behavior was investigated in people who were discharged immediately to the home setting. In addition, the course of movement behavior outcomes (amount of SB, LPA, MVPA, MVPA accumulated in bouts ≥ 10 minutes and weighted median sedentary bout length) within the first two months after discharge from hospital care was assessed. Possible subgroup trajectories within this timeframe were studied.

Although the independent health benefits of sufficient amounts of MVPA and low amounts of SB are highlighted in research, these single aspects are not self-contained but cluster in patterns. Therefore, in **Chapter 6**, the identification of movement behavior patterns in people with stroke is described, and associations per movement behavior pattern are investigated. **Chapter 7** investigated the long-term association of physical functioning and the identified movement behavior patterns. **Chapter 8** describes the identification of behavior change techniques that should be included in a behavioral change intervention directed at reducing sedentary behavior in people with stroke.

A general discussion is provided in **Chapter 9**. In this chapter, the most important findings are discussed. Implications for clinical practice, education, and recommendations for future research are included in this chapter.

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CHAPTER 2



THE COURSE OF ACTIVITIES IN DAILY LIVING: WHO IS AT RISK FOR DECLINE AFTER FIRST-EVER STROKE

Roderick Wondergem

Martijn F. Pisters

Eveline J.M. Wouters

Nick Olthof

Rob A. de Bie

Johanna M.A. Visser-Meily

Cindy Veenhof

Abstract

Background

Stroke is not only an acute disease but for the majority of patients, it also becomes a chronic condition. There is a major concern about the long term follow-up with respect to activities of daily living (ADL) in stroke survivors. Some patients seem to be at risk for a decline after a first-ever stroke. The purpose of this study was to determine the course of ADL from three months after the first-ever stroke and onward and identify factors associated with the decline in ADL.

Methods

A systematic literature search of three electronic databases through June 2015 was conducted. Longitudinal studies evaluating changes in ADL from three months post-stroke onwards were included. Cohorts, including recurrent strokes and transient ischemic attacks, were excluded. Regarding the course of ADL, a meta-analysis was performed using random-effects model. A best-evidence synthesis was performed to identify factors associated with the decline in ADL.

Results

Out of 10,473 publications, 28 unique studies were included. A small but significant improvement in ADL was found from three to twelve months post-stroke (SMD 0.17 [0.04-0.30]), which mainly seemed to occur between three and six months post-stroke (SMD 0.15[0.05-0.26]). From one to three years post-stroke, no significant change was found. Five studies found a decline in ADL status over time in twelve to forty percent of patients. Nine factors were associated with ADL decline. There is moderate evidence for being dependent in ADL and impaired motor function of the leg. Limited evidence was found associated with insurance status, living alone, being age eighty or older, being inactive, and having impaired cognitive function, depression, and fatigue with the decline in ADL.

Conclusion

Although on average patients do not seem to decline in ADL for up to three years, there is considerable variation within the population. Some modifiable factors associated with the decline in ADL were identified. However, more research is needed before patients at risk of deterioration in ADL can be identified.

Introduction

Advances in the acute medical treatment of stroke have resulted in improved survival rates during the last few decades. Stroke is not only an acute disease but for the majority of patients, it also develops into a chronic condition. A growing number of people live with the consequences of stroke, resulting in an expected nineteen percent increase in the global stroke burden in the next two decades¹⁻⁴.

In 2011, Langhorne et al. launched a hypothetical functional recovery model after stroke, postulating that recovery of body functions and activities reaches a plateau phase between three and six months post-stroke. After six months post-stroke, it is hypothesized that some patients decline, while, on average, patients remain stable or improve⁵. It remains, however, unclear whether the hypothesized functional recovery model can be confirmed based on the existing literature.

Integrated stroke services have been developed to provide multidisciplinary, coordinated care during the first months when acute care and rehabilitation are prominent⁶. However, a major concern is a poor long-term follow-up with respect to problems in activities of daily living (ADL), an essential determinant for social reintegration⁷.

Therefore, the aim of this systematic review is 1) to determine the course of ADL in the period between three months and onward following first-ever stroke and 2) to identify factors associated with the decline in ADL. Early identification of patients at risk for a decline in ADL might enable professionals to provide adequate support and monitoring to these patients to prevent decline.

Methods

In- and exclusion criteria

Studies eligible for this review met the following inclusion criteria: 1) evaluating changes in ADL (domains d4 mobility and d5 self-care of the ICF-model without moving around with transportation d470- d489)⁸ after first-ever clinical confirmed focal neurological deficit due to cerebrovascular disease over a period of at least six months from three months post-stroke; 2) age \geq 18 years; 3) peer-reviewed full-text publications published in English, German or Dutch. Studies that included patients with transient ischemic attacks, subarachnoid hemorrhage or subdural hematoma were excluded. In cases of multiple publications on the same cohort study presenting different information, reporting on different factors associated with the decline in ADL, or presenting results after different follow-up periods, all publications were included. However, multiple publications on the same cohort study were considered as one unique cohort study if the inclusion period of patients was equal or overlapped.

Literature search

The review was conducted following the recommendations of the statement Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)⁹. The literature was searched until June 2015 within PubMed¹⁹⁶⁶, EMBASE¹⁹⁸⁰, and CINAHL¹⁹⁸². The search strategy was formulated in PubMed (Appendix table I) and adapted for use in other databases. It consisted of three components: 1) stroke (adapted from Verbeek et al.¹⁰); 2) longitudinal cohort studies (following the recommendation for search strings of the Cochrane collaboration); and 3) ADL. Reference lists of included publications and relevant reviews were screened for possible additional relevant publications by one reviewer (RW).

Selection procedure

The study selection was performed by two independent reviewers (RW and NO) in two steps: 1) title and abstract; and 2) relevant full-text reports. Disagreements were resolved by discussion. If an agreement was not achieved, a third reviewer (MFP) was consulted.

Methodological quality

Methodological quality of included publications was independently assessed by two reviewers (RW and NO) using the Quality in Prognosis Studies (QUIPS) tool for potential risk of bias (Appendix table II)¹¹. The QUIPS tool assesses six domains: 1) study participation; 2) study attrition; 3) prognostic factor measurement; 4) outcome measurement; 5) study confounding; and 6) analysis and reporting. Item 5 was not rated because this review does not focus on causality between a single prognostic factor and outcome. The other domains received an overall judgment of “high”, “moderate” or “low” risk of bias based on the

items within the domains. Publications that scored “high” for risk of bias on at least one domain were considered low quality. Differences in scoring between the two reviewers were discussed. If no consensus was reached, a third reviewer (MFP) was consulted.

Data extraction

One reviewer (RW) extracted the following information from the included publications: unique studies, number of publications per study, authors, year of publication, setting, year of recruitment, inclusion and exclusion criteria, outcome measures, time-points of follow-up, ADL outcome for the different time-points, associated factors and percentage of the population who declined in ADL. When only dichotomized, ordinal, or visually presented data were available for ADL outcome at the different time-points, the authors were requested to provide the number of subjects, mean and standard deviation.

Data analyses

Quantitative analyses were performed if at least three high-quality studies included data on the same time course using Review Manager 5.3 (RevMan. Copenhagen: the Nordic Cochrane Centre, The Cochrane Collaboration, 2008). Time courses from three to twelve months post-stroke and from twelve months to long-term follow-up were analyzed. Sub-analyses were performed if the data in the included publications were available from three to six months and from six to twelve months post-stroke. The means and standard deviations of the follow-up measurements or the change in scores between both follow-up measurements with the standard deviation were converted to a standardized mean difference (SMD) score, and the 95% confidence interval (CI) was calculated. Pooling was performed using a random-effect model. Changes over time in ADL were considered small if the SMD was <0.2 , moderate if the SMD was between $0.2 - 0.8$, or high if the SMD ≥ 0.8 ¹². If both performance-based data and self-reported data were provided, performance-based data were used. The data of the Barthel Index was used over other data¹³. I^2 was used to test heterogeneity between studies. The I^2 was considered to be low ($\leq 25\%$), moderate (26-50%), or high ($>75\%$)¹⁴. Sensitivity analyses were performed using both high and low-quality studies.

Because it was impossible to perform quantitative analysis for factors associated with a decline in ADL, a best evidence synthesis (BES) was performed. The BES consists of five levels of evidence (strong, moderate, limited, inconsistent, and no evidence). Conclusions were based on the number of studies evaluating the factor, consistency of results, and methodological quality (Table 1)¹⁵. When the results of univariate analyses were available, these were used in the BES; otherwise, the estimates of multivariate analyses were used.

In case of multiple publications based on the same cohort study (e.g., data from Orebro study, South London Stroke Register, NOMASS-study and FuPro study), we used the results of the publication in the quantitative or qualitative analyses with 1) the highest quality; 2) the longest follow up period; 3) the largest cohort or 4) reported results of univariate analyses instead of associations of multivariate analyses.

Table 1. Level of evidence for associations with a decline in ADL.

Level of evidence	
Strong	Consistent significant findings in at least two high-quality studies
Moderate	Consistent significant findings in one high-quality study and at least one low-quality study
Limited	Consistent significant findings in one high-quality study or consistent findings in at least three low-quality studies
Conflicting	Conflicting significant findings in high-quality studies (i.e., <75% of the studies reported consistent findings)
No evidence	No high quality studies could be found

Results

The search strategy yielded 10,473 publications. A flow-chart is presented in Figure I. In total, 28 unique studies were included, based on 36 publications^{13,16-50} that fulfilled all selection criteria. Six studies recruited populations from a rehabilitation setting (18,19,29,34,40, FuProStudy:13,38,45,46) and the other studies included hospital-based populations. An overview of the study characteristics is presented in Appendix table III. The main reason for exclusion was the absence of follow-up measurements over a period of at least six months from three months post-stroke.

Methodological quality

In total, 20^{16,20,24-32,34,35,38-41,43-45} of the 36 publications were rated as high quality (Appendix table IV). The main reason for downgrading the quality of a study was a high risk of bias in the study attrition domain^{13,17-19,21,33,42,46-49,51}. In 87.1% of the 170 methodological items, there was agreement. In all cases, a consensus was reached after discussion between the two reviewers.

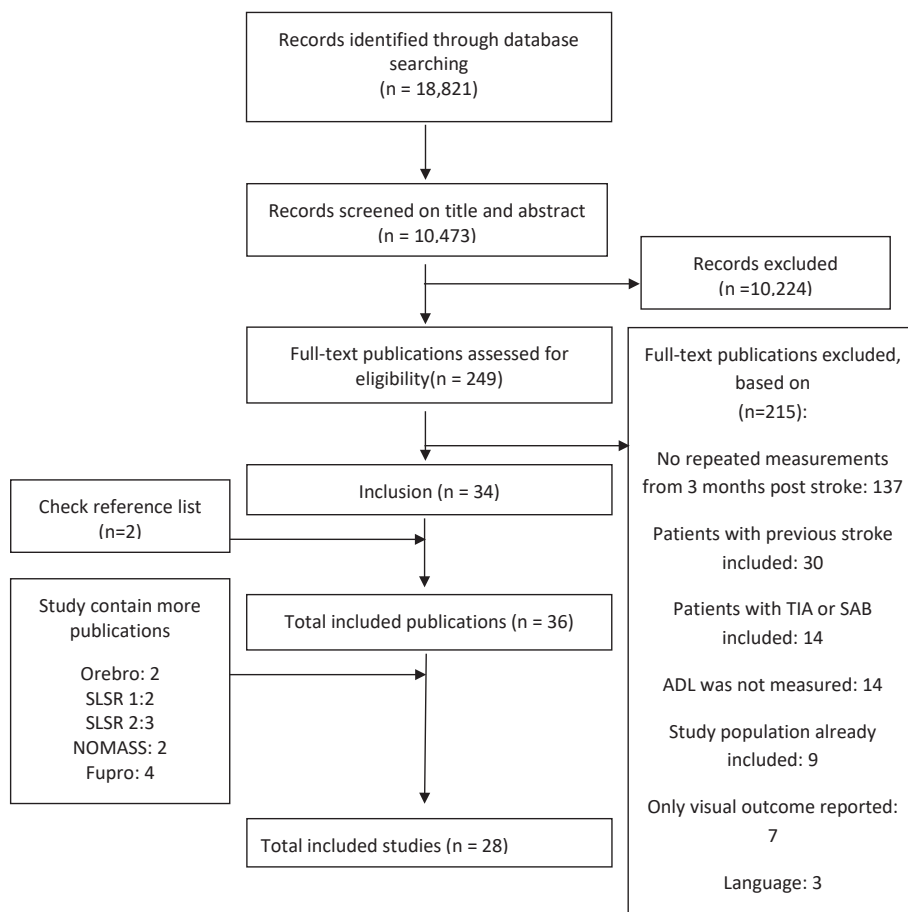


Figure I. Screening for eligibility

Changes in ADL status over time

The results showed a small but significant improvement (SMD 0.17 [0.04-0.30] $P < 0.05$, $I^2 = 67\%$) in ADL from three to twelve months (Figure IIA). The sub-analysis revealed that this improvement mainly occurred between three to six months. In this period, a small but significant improvement in ADL was found (SMD 0.15 [0.05-0.26] $P < 0.05$) with low to moderate heterogeneity ($I^2 = 29\%$) (Figure IIB). The sub-analysis from six to twelve months showed no significant improvement in ADL (Figure IIC) with moderate to high heterogeneity (SMD 0.07 [-0.06, 0.20] $P = 0.28$, $I^2 = 61$). Sensitivity analyses, including both low and high-quality studies, showed similar results with high heterogeneity (Appendix table V).

For the analysis from twelve months to longer-term follow-up, two low-quality studies^{17,48} and one high-quality study⁴⁵ were available. The data until three years of follow-up were

used. Within this time period, a non-significant decline in ADL was observed with low heterogeneity (SMD -0.02 [-0.08,0.05] $P=0.58$, $I^2=0\%$) (Figure IID).

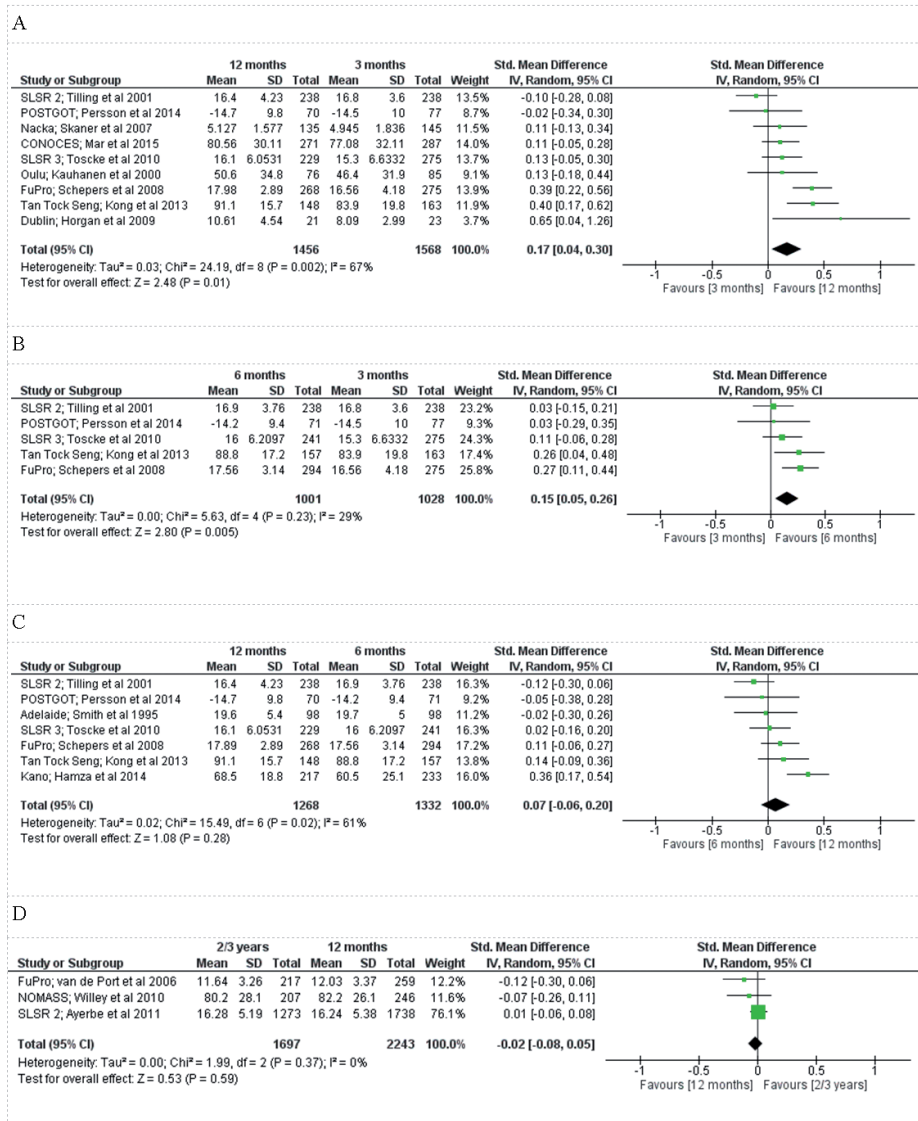


Figure II. Standardized mean difference of the course of activities of daily living between 3 and 12 months (A), 3 and 6 months (B), 6 and 12 months (C), 12 months and 2/3 years (D). A positive mean difference score indicates an improvement in activities of daily living-function.

Std.= standardized, SD=standard deviation, CI= confidence interval, I^2 = Heterogeneity

The proportion of the population that declined, maintained, or improved in ADL was reported within five studies (28,38,42,50 and FuPro study 48,49) (Table 2). These studies reported that between twelve and forty percent of the study population decline in ADL in the period between three months post-stroke and long-term follow-up. However, within these studies, different cut-off points, outcome measures, and follow-up periods were used.

Table 2. Percentage of stroke population, which declined, maintained, or improved in ADL.

<i>Author</i>	<i>Recruitment</i>	<i>Outcome measure</i>	<i>Time point</i>	<i>N (improve/ maintain/ decline)</i>
<i>Wilkinson et al. 1997</i>	Hospital	Barthel Index	3 months – 5 years	N=103 (7%/54%/39%)
<i>Harwood et al. 1997</i>	Hospital	London Handicap scale	1 year- 3 year	N=58 (26%/41%/19%)
<i>Persson et al. 2014</i>	Hospital	Time up and Go	3 months – 6 months 6 months – 12 months	N=71 (41%/32%/27%) N=67 (36%/22%/42%)
<i>Skaner et al. 2007</i>	Hospital	Katz scale	3 months – 12 months	N=125 (0%/75%/25%)
<i>Fupro study:</i> <i>1. van Wijk et al. 2006</i> <i>2. Van de Port et al. 2006</i>	Rehabilitation center	Rivermead mobility index	1. 1 year – 2 years 2. 1 year – 3 years	N=148 (6.9%/79.9%/12.2%) N=202 (7%/72%/ 21%)

Factors associated with ADL decline over time

Researchers described within five unique studies^{20,35,42,45,49} a total of nine factors associated with a decline in ADL. Moderate evidence was found for ‘being dependent in ADL’^{45,49} and ‘impaired motor function of the leg’^{42,45}. Limited evidence was found for ‘Medicaid/having no insurance’²⁰, ‘living alone’⁴⁵, ‘age ≥ eighty’³⁵, ‘being inactive’⁴⁵, ‘impaired cognitive function’⁴⁵, ‘presence of depression’⁴⁵ and ‘presence of fatigue’⁴⁵.

Discussion

In this study, the course of ADL in the period between three months after the first-ever stroke and longer-term was explored as well as factors associated with a decline in ADL status. The results from this review showed a small but statistically significant improvement in ADL between three and twelve months post-stroke. However, this improvement mainly occurred between three and six months, and the results also suggest that ADL status seems to remain stable from one to three years of post-stroke.

Changes in ADL status over time

The results are in accordance with the hypothesized model of Langhorne et al.⁵, illustrating that ADL recovery seems to reach a plateau phase somewhere between three and six months post-stroke. Although the results suggest that ADL status remains relatively stable after six months post first-ever stroke, these results might be biased. The studies used in the meta-analyses included populations recruited from hospital-based settings, severe subpopulations recruited from hospital-based settings, and studies using a study population recruited from a rehabilitation based setting. It can be hypothesized that especially the more severe hospital populations, as well as the rehabilitation populations, will have a different course in ADL status over time. Also, the different types of ADL outcomes measures used within the included studies might have influenced the results. The majority of the studies used the Barthel Index. The responsiveness to change might be different for mobility measures since these do not include self-care items. However, when analyzing a more homogenous population (using only studies that recruited the study population from a hospital setting, using instruments that measure the full spectrum of ADL), showed comparable results (Appendix material figure IA and IB).

Furthermore, studies reporting the proportion of the population that declines in ADL status suggest that twelve to forty percent of the patients decline in ADL status in the period between three months and the longer-term post first-ever stroke. Although the reported percentages indicate considerable variation within the population, these percentages should be interpreted with caution due to the heterogeneity among these studies (e.g., in cut-off points, outcome measures, and follow-up periods used). On the other hand, in a Swedish study 35 000 unselected stroke patients (both first-ever (81%) and recurrent (19%) were followed up at three and twelve months follow-up (ADL outcome was mobility, toilet, and dressing). The study found a 16% decline among survivors, from a level of independence in ADL to a level of dependence in ADL⁵². Although these results are not generalizable to a population of patients with exclusively first-ever stroke, the findings of this study are in agreement with the findings from our review. For future research, it will be essential to focus

on the clinically relevant decline in ADL –status or decline from a level of independence to a level of dependency.

Factors associated with ADL decline over time

Only five studies were found describing nine factors associated with the decline in ADL status from three months after stroke and onward. When patients are dependent with respect to ADL, they are at risk of declining further in their ADL status. Also, patients with impaired motor function of the leg (including impaired leg function⁴⁵ and paralysis of the leg⁴²) seem to be at risk for a decline in ADL status. Impaired ADL and motor function may contribute to a more physically inactivity lifestyle⁵³. Physical inactivity, in turn, could result in a reduction in cardiorespiratory fitness and muscle strength, leading to a further decline in ADL status⁵³. In the current study, although limited, evidence was found for the association between inactivity and decline in ADL status. However, inactivity was measured with the Frenchay Activities Index, which measures the self-perceived level of functional activities. Less is known about physical behavior, the amount of physical activity and sedentary time in the context of ADL status⁵⁴ in patients after stroke, especially with respect to long-term changes in ADL status⁵⁵. Besides physical impairments, other modifiable factors, such as cognitive function, depression, and fatigue, might contribute to declining in ADL status as well and, therefore, should be addressed in future research.

Study limitations

The most common source of bias in the included studies was attrition bias. Most studies recruited participants from a hospital setting, in which earlier research has shown relatively high mortality rates of twenty-five percent within the first year^{59,60}. Consequently, this might have biased our results, because patients with poor functional outcome have a higher short term mortality risk since poor outcome at three months is a strong predictor of death⁵⁶. Because of the drop-out of deceased patients in follow-up analyses, the results on the course in our review in the first year follow-up and onward might be an overestimation of the ADL status. Furthermore, on average, per year, ten percent of the participants in the included studies were lost to follow-up due to a variety of reasons. In most studies, a description of differences between completing participants and dropouts was lacking.

As mentioned earlier in the discussion, one of the limitations of our study was the heterogeneity of included studies in a patient population, ADL outcomes used, different follow-up times and intervals, and different local treatment/rehabilitation traditions. Unfortunately, due to the limited number of studies that could be included in the meta-analysis, not all relevant subgroup analyses could be performed. When we interpreted the heterogeneity, we found moderate to high heterogeneity between studies on the time course from three to twelve months. However, within the sub-analyze between

three and six months, only a heterogeneity of 29% was found, indicating limited to moderate heterogeneity. The heterogeneity can be explained because the hospital-based population remained relatively stable, whereas the rehabilitation populations still showed improvement. Within the sub-analysis between six to twelve months, the heterogeneity was mainly due to the study by Hamza et al.²⁴, which had a major effect on the heterogeneity. When excluding this study from the analysis, the heterogeneity declined to zero. However, the SMD remained non-significant but changed to 0.02 [-0.07,0.10]. The differences in study populations might offer a possible explanation for the different results between this study and the others. The population in the study performed by Hamza et al. was Nigerian, and the differences in health care systems between western countries and developing countries must not be underestimated⁵⁷.

Conclusion

Although on average, patients do not seem to decline in ADL for up to three years, there is considerable variation within the population. Some modifiable factors associated with the decline in ADL were identified. However, more research is needed before patients at risk of deterioration in ADL can be identified.

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Appendix

Table I. Keywords and additional search strategy Pubmed

Category	Patient	Outcome	Others
Keywords	Stroke	ADL	Design
1.	(Stroke[Mesh] OR cva OR cvas OR poststroke OR stroke* OR apoplexy)	5. "mobility limitation" [Mesh]	12. "Epidemiologic studies" [mesh]
2.	(((brain* OR cerebr* OR cerebell* OR intracran* OR intracerebral* OR vertebrobasilar) AND vascular*) OR cerebrovascular*) AND (accident OR accidents)	6. "Activities of Daily Living"[Mesh] OR adl OR iadl	13. "Cohort studies"[mesh]
3.	(brain* OR cerebr* OR cerebell* OR intracran* OR intracerebral* OR vertebrobasilar) AND (haemorrhag* OR hemorrhag* OR ischemi* OR ischaemi* OR infarct* OR haematoma* OR hematoma* OR bleed*)	7. self-care	14. #12 OR #13
4.	(#1 OR #2 OR #3)	8. mobilit*	15. Cohort
		9. disabilit*	16. Study or Studies
		10. functional outcome OR functional status OR functional decline	17. #15 AND #16
		11. #5 OR #6 OR #7 OR #8 OR #9 OR #10	18. Analy*
			19. #18 AND #16
			20. Follow-up
			21. #20 AND #16
			22. Longitudinal
			23. Retrospective
			24. Observational
			25. #24 AND #16
			26. Prospective
			27. #14 OR #17 OR #19 OR #21 OR #22 OR #23 OR #25 OR #26

* All terms were searched with the adding title/abstract

Total search strategy:

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(((((((functional decline[Title/Abstract]) OR functional status[Title/Abstract]) OR functional outcome[Title/Abstract]) OR self-care[Title/Abstract]) OR disabilit*[Title/Abstract]) OR mobilit*[Title/Abstract]) OR "mobility limitation"[MeSH Terms]) OR (((("activities of daily living"[MeSH Terms]) OR "adl"[Title/Abstract]) OR "iadl"[Title/Abstract])) AND (((((((("epidemiologic studies"[MeSH Terms]) OR "cohort studies"[MeSH Terms]) OR ((("cohort"[Title/Abstract]) AND ((study[Title/Abstract]) OR "studies"[Title/Abstract]))) OR ((analy*[Title/Abstract]) AND ((study[Title/Abstract]) OR "studies"[Title/Abstract]))) OR ((follow-up[Title/Abstract]) AND ((study[Title/Abstract]) OR "studies"[Title/Abstract]))) OR "longitudinal"[Title/Abstract]) OR "retrospective"[Title/Abstract]) OR ((observational[Title/Abstract]) AND ((study[Title/Abstract]) OR "studies"[Title/Abstract]))) OR prospective[Title/Abstract]))) AND (((((((stroke[MeSH Terms]) OR (cva[Title/Abstract]) OR (cvas[Title/Abstract]) OR (poststroke[Title/Abstract]) OR (stroke*[Title/Abstract])) OR (apoplexy[Title/Abstract]) OR (((brain*[Title/Abstract]) OR (cerebr*[Title/Abstract]) OR (cerebell*[Title/Abstract]) OR (intracran*[Title/Abstract]) OR (intracerebral*[Title/Abstract]) OR (vertebrobasilar[Title/Abstract])) AND (vascular*[Title/Abstract]) OR (cerebrovascular*[Title/Abstract])) AND (accident*[Title/Abstract]) OR (((brain*[Title/Abstract]) OR (cerebr*[Title/Abstract]) OR (cerebell*[Title/Abstract]) OR (intracran*[Title/Abstract]) OR (intracerebral*[Title/Abstract]) OR (vertebrobasilar[Title/Abstract])) AND ((haemorrhag*[Title/Abstract]) OR (hemorrhag*[Title/Abstract]) OR (ischemi*[Title/Abstract]) OR (ischaemi*[Title/Abstract]) OR (infarct*[Title/Abstract]) OR (haematoma*[Title/Abstract]) OR (hematoma*[Title/Abstract]) OR (bleed*[Title/Abstract]))))))))
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Table II. Bias domains and items of the QUIPS tool

POTENTIAL BIAS	ITEMS	YES/PARTIAL/ NO/UNSURE	RATING	QUALITY PUBLICATION (HIGH/LOW)
1. STUDY PARTICIPATION PROMPTING ITEMS AND CONSIDERATIONS	<ul style="list-style-type: none"> a. Adequate participation in the study by eligible persons b. Description of the source population or population of interest c. Description of the baseline study sample d. Adequate description of the sampling frame and recruitment e. Adequate description of the period and place of recruitment f. Adequate description of inclusion an exclusion 		The relationship between the PF and outcome is very likely to be/may be/is unlikely to be different for participants and eligible nonparticipants	
2. STUDY ATTRITION THE STUDY DATA AVAILABLE ADEQUATELY REPRESENT THE STUDY SAMPLE	<ul style="list-style-type: none"> a. Adequate response rate for study participants b. Description of attempts to collect information on participants who dropped out c. Reasons for loss to follow-up are provided d. Adequate description of participants lost to follow-up e. There are no important differences between participants who completed the study and those who did not 		The relationship between the PF and outcome is very likely to be/ may be/ unlikely to be different for completing and non-completing participants	
3. PROGNOSTIC FACTOR MEASUREMENT THE PF IS MEASURED IN A SIMILAR WAY FOR ALL PARTICIPANTS	<ul style="list-style-type: none"> a. A clear definition or description of the PF is provided b. Method of pf measurement is adequately valid and reliable c. Continuous variables are reported or appropriate cut points are used d. The method and setting of measurement of pf is the same for all study participants e. Adequate proportion of the study sample has complete data for the PF f. Appropriate methods of imputation are used for missing PF data 		The measurement of the PF is very likely to be/may be/ unlikely to be different for different levels of the outcome of interest	

Table II. (Continued)

POTENTIAL BIAS	ITEMS	YES/PARTIAL/ NO/UNSURE	RATING	QUALITY PUBLICATION (HIGH/LOW)
4. OUTCOME MEASUREMENT THE OUTCOME OF INTEREST IS MEASURED IN A SIMILAR WAY FOR ALL PARTICIPANTS	<ul style="list-style-type: none"> a. A clear definition of the outcome of interest is provided b. Method of outcome measurement used is adequately valid and reliable c. The method and setting of outcome measurement is the same for all study participants 		The measurement of the outcome is very likely to be/ may be / unlikely to be different related to the baseline level of the PF	
5. STATISTICAL ANALYSIS AND REPORTING THE STATISTICAL ANALYSIS IS APPROPRIATE, AND ALL PRIMARY OUTCOMES ARE REPORTED	<ul style="list-style-type: none"> a. Sufficient presentation of data to assess the adequacy of the analytic strategy b. Strategy for model building is appropriate and is based on a conceptual framework or model c. The selected model is adequate for the design of the study d. There is no selective reporting of results. 		The reported results are very likely to be/ may be/ unlikely to be spurious or biased related to analysis or reporting	

Table III. Characteristics of included studies (N=30) and publications (K=38)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
1. Orebro-study (2)	Appelros et al 2005 (1)	Setting: Emergency care unit Orebro University Hospital (1989-1992) Inclusion: first ever stroke, lacunar as dependent syndrome	KATZ (P-adi: bathing, dressing, toileting, transfer, continence and feeding) Equal to level A were defined as dependent 1, 3 and 5 years N=81	No associations with decline in ADL presented	1 year 51(63%) independent 3 years 44(55%) independent 5 years 36(44%) independent 1 year 10(12%) dependent P-ADL 3 years 18(22%) dependent P-ADL 5 years 14(17%) dependent P-ADL 1 year 1(1%) dead 3 years 5 (6%) dead 5 years 15(19%) dead Others were dependent in I-ADL (cooking, transportation, shopping and cleaning)
2. SLRS 1(2)	Samuelsson et al 1996 (2)	Setting: Medical center hospital Orebro and Stockholm (1989-1992) Inclusion: first ever stroke, lacunar infarction	KATZ ADL (P-adi: bathing, dressing, toileting, transfer, continence and feeding; I-adi: cooking transporting, shopping, cleaning) Considered to be independent if they were able to perform when left alone 6 months, 1 and 3 years post stroke N=81	No associations with decline in ADL presented	6 months 52(64%) independent 1 year 51(63%) independent 3 years 44(55%) independent 6 months 10(12%) dependent P-ADL 1 year 10(12%) dependent P-ADL 3 years 18(22%) dependent P-ADL 6 months 0 dead 1 year 1(1%) dead 3 years 5(6%) dead Others were dependent in I-ADL (cooking, transportation, shopping and cleaning)
2. SLRS 1(2)	Taub et al 1994 (3)	Setting: SLRS, Three district health authorities in southeast England (1989-1991) Inclusion: first-time stroke according to WHO, age<75 Exclusion: disabled before stroke	BI between 3-12 months N=109	The associations of change in BI with demographic characteristics and with severity indicators assessed at 3 months were examined, and only paralysis was found to be significant at the 5% level (P=0.04, Mann-Whitney test).	There was no evidence of change in BI scores between 3 and 12 months (two sided Wilcoxon test P>0.1)
2. SLRS 1(2)	Wilkinson et al 1997 (4)	Setting: SLRS a community stroke register was established in southeast London (1989-1990) Inclusion: stroke according WHO, first ever stroke, age <75	BI (very severely, severely disabled, moderate disabled, mildly disabled, independent) between 3 months - 5 years N=103	No associations with decline in ADL presented	BI 3 months-5 years 56(54%) same category, 7(7%) improved, 40(39%) deteriorated

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
3. SLRS 2 (3)	Tilling et al 2001 (5)	Setting: SLRS, St Thomas's and King's College Hospitals London (Jan 1993-July 1995) Inclusion WHO definition of stroke, needed to be able to perform transfer with assistance. Exclusion if patients lived too far to visit	BI 13 weeks, 22 weeks, 31 weeks and 57 weeks after stroke N=238	The effect of age, dysphasia and limb deficit at baseline on BI varied over time. Age >80 improved faster but then show a sharper long-term decline. Dysphasia tended to improve faster but after 12 weeks the recovery curves with and without dysphasia appeared to be parallel. Those with limb deficit improved quickly initially but then showed a slightly steeper long term decline.	BI score 13 weeks Mean 16.8 (SD 3.60) BI score 22 weeks Mean 16.9 (SD 3.76) BI score 31 weeks Mean 16.8 (SD 3.96) BI score 57 weeks Mean 16.4 (SD 4.23)
Ayerbe et al 2011(6)	Setting: SLRS (Jan 1995-1999) Inclusion: Stroke definition WHO Exclusion: Severe cognitive or communication impairment	BI % of 20 points (maximum score) 3 months N=1821 1 year N=1752 3 years N=1353 5 years N=742	No associations with decline in ADL presented	Data* BI 3 months 15.33 SD 5.92 N=1805 BI 1 year 16.24 SD 5.38 N=1738 BI 3 years 16.28 SD 5.19 N=1273 BI 5 years 16.42 SD 4.87 N=687	
Wolfe et al 2011 (7)	Setting: SLRS (Jan 1995-1999) Inclusion: Stroke definition WHO Exclusion	BI 3 months N=1679 1 year N=1578 2 years N=1087 3 years N=1209 4 years N=1002 5 years N=726 6 years N=622 7 years N=494 8 years N=408 9 years N=283 10 years N=223	No associations with decline in ADL presented	Data* BI 3 months 15.27 SD 5.94 N=1664 BI 1 year 16.18 SD 5.41 N=1565 BI 2 years 16.40 SD 5.14 N=1076 BI 3 years 16.19 SD 5.26 N=1160 BI 4 years 16.25 SD 5.26 N=963 BI 5 years 16.42 SD 4.87 N=687 BI 6 years 16.29 SD 5.13 N=617 BI 7 years 15.90 SD 5.49 N=482 BI 8 years 15.73 SD 5.79 N=400 BI 9 years 15.57 SD 5.81 N=278 BI 10 years 15.38 SD 5.85 N=212	

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
4. SLRS 3 (1)	Toschke et al 2010 (8)	Setting: SLRS (2002-2004) Inclusion WHO criteria, at least two follow-up measures and informed consent	BI 12 weeks N=275 26 weeks N=241 52 weeks N=229	No associations with decline in ADL presented	BI 12 weeks mean 15.3 (SE0.4) BI 26 weeks mean 16.0 (SE0.4) BI 52 weeks mean 16.1 (SE0.4)
5. Leuven (1)	Baert et al. 2012 (9)	Setting: Rehabilitation unit University Hospital Leuven Inclusion: Patients from stroke rehabilitation unit, <75 years, able to comprehend simple test, no other neurological disorders, no stroke-like symptoms due to other pathology, no prestroke BI<50, able to perform a maximal exercise test	RMAGF, BI TMWT 3 months N=32 6 months N=31 12 months N=31 (TMWT N=26,27,28)	No associations with decline in ADL presented	Article 3 months RMAGF median 11 (IQR10-12) 6 months RMAGF median 11 (IQR10-13) 12 months RMAGF median 12 (IQR10-13) 3 months BI median 95 (IQR85-100) 6 months BI median 95 (IQR85-100) 12 months BI median 95 (IQR80-100) 3 months TMWT m/s Mean 1.52(SD 0.28), 6 months TMWT m/s mean 1.43(SD 0.49) 12 months TMWT m/s mean 1.41(SD 0.53) Data* BI 3 months mean 89.8 (SD 13.8) BI 6 months mean 90.0 (SD 13.0) BI 12 months mean 89.7 (SD 13.0)
6. Midwestern Medical Center (1)	Callahan et al 2005 (10)	Setting: Hospital based acute inpatient rehabilitation unit Inclusion: residual physical, functional and/or cognitive deficits related to CVA Exclusion: refusal participation, cognitive or aphasic syndrome that precluded survey completion	SF-36 PF scale 6 months N=172 12 months N=71	No associations with decline in ADL presented	Data* SF-36 PF 6 months mean 30.79 SD 18.79 SF-36 PF 12 months mean 31.19 SD 29.19
7. NOMASS (2)	Dhmoon et al 2009 (11)	Setting: NOMASS study(1993-1996) Inclusion: population based incident ischemic stroke, fir stroke, age≥40, resided in northern Manhattan for ≥3 months	BI 6 months N=572 12 months N=525	Changes of BI over time differed significantly by insurance status Medicaid/no insurance vs medicare/private insurance.	Annual decline in proportion BI≥95 (OR per year 0.96(95%CI0.92-1.01) Subgroups analysis for participants with BI≥95 at 6 months (n=245) unadjusted OR 0.81 p<0.0001. The maximum likelihood estimate of the change point was at 3 years, whereas change in proportion of participants with BI≥95 before and after 3 years was p=.0088

Table III. (Continued)

Study number of publications	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
	Willey et al 2010 (12)	Setting: NOMASS (1993-1997) Inclusion: first ever ischemic stroke, age >39, resident of Northern Manhattan for more than three months, access to a telephone Exclusion: TIA, haemorrhage	BI (severe disability BI<60, moderate disability BI 60-95, no disability BI≥95) 1 year N=247, 2 years N=207	No associations with decline in ADL presented	1 year: No disability: 136 (55%), moderate disability: 71 (29%), severe disability 39 (16%) 2 year: No disability: 109(53%), moderate disability: 61(29%), severe disability 37(18%) Data* 1 year BI score mean 82.2(SD26.1) N=246 2 years BI score mean 80.2 (SD28.1) N=207
8. Kitasato (1)	Fukuda et al 2009 (13)	Setting: Department of Neurology at Kitasato University Hospital (1986-2000) Inclusion: hospitalized within 3 days after stroke, ischemic stroke	Functional status expressed as locomotor activity (1. No significant disability in walking 2. Slight disability (walking with-out the aid of a cane or braces) 3. Moderate disability (walking with a cane and/or braces) 4. Moderately severe disability (using a wheelchair) 5. Severe disability (bedridden) 1 year N=879, 5 years N=547	No associations with decline in ADL presented	Year 1 1: 52.7%; 2: 19.7%; 3: 15.0%; 4: 8.3%; 5: 4.3% Year 5 1:56.5%; 2: 15.7%; 3: 16.4%; 4: 7.1%; 5: 4.2%
9. Ibadan (1)	Gbiri et al 2013 (14)	Setting: University college hospital Ibadan Nigeria Inclusion: first ever stroke	BADL measured by BI N=55	No associations with decline in ADL presented	Data*: 3 months mean BI 40 (SD15) 4 months mean BI 65 (SD20) 5 months mean BI 75 (SD20) 6 months mean BI 85(SD25) 7 months mean BI 95 (SD20) 8 until 12 months mean BI 100 (SD0)

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
10. Goteborg 70+ (1)	Gosman et al 2004 (15)	Setting: Goteborg 70+ study Inclusion criteria: ≥ 70 years living in their own homes prior to stroke. Exclusion criteria: onset of symptoms >7 days before admission to the stroke unit, known cerebral lesion, extra cerebral or subarachnoid haemorrhage or brain tumor, coma and indication of specialized management at the department of neurology	FIM motor score between 3 months and 1 year N=173	No associations with decline in ADL presented	Total FIM score 3 months mean 75.56 Total FIM score 1 year mean 73.61
11. Kano (1)	Hamza et al 2014 (16)	Setting: One Teaching and two specialist hospitals in Kano state Nigeria(2010-2011) Inclusion: First ever stroke, age≥ 18 years, receiving rehabilitation. Exclusion: recurrent stroke, persistent deficits with underlying psychotic and mental disorders and comorbidities that significantly affect QoL.	BI, SIS mobility and ADL 6 months N=233, 12 months N= 217	No associations with decline in ADL presented	BI 6 months: 60.5 (SD 25.1) 12 months: 68.5 (SD 18.8) change mean 8.0(SD 8.7) SIS ADL: 6 months 46.4 (SD 24.8), 12 months 52.2 (SD22.7) change 5.4 (SD5.1) SIS Mobility: 6 months 49.8 (SD30.5), 12 months 54.1 (SD27.6) change 3.6 (SD4.7) All p<0.001
12. East London (1)	Harwood et al 1997 (17)	Setting: Two East London health districts. Two major hospitals, stroke unit (period 1 year) Inclusion: Stroke according to WHO. No further inclusion given	LHS, mobility and physical independence domain (both six points scales) Change between 1-3 years N=58	No associations with decline in ADL presented	Mobility change score: Deteriorated 11 (19%), no change 29 (51%), improved 17 (30%), median change 0, range of changes -2,+4, wilcoxon test p=0.37 Physical independence change score: Deteriorated 19(33%), no change 24 (41%), improved 15(26%), median change 0, range of changes -2+3, wilcoxon test p=0.58

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
13. Dublin (1)	Horgan et al 2009 (18)	Setting: Two major teaching hospitals in Dublin (8 months period) Inclusion: First stroke with residual hemiparesis, still inpatient at 2 weeks post onset, age>18 years, OPS score>3.2 or <5.2 at 2 weeks, no history of pre-existing neurological disorders or orthopaedic conditions limiting mobility or unstable blood pressure and demonstrated no severe deficits in communication or understanding.	SAS Over 1 year N=23	No associations with decline in ADL presented	Mean change SAS: Week 12-24 0.87 (SE0.70) Week 24-36 0.78 (SE0.70) Week 36-48 0.87 (SE0.70) Changes significant between 2-48 weeks mean change 8.1 (p<0.0001), 12-48 weeks 3.4(p<0.0001) and 24-48 weeks 2.3 (p<0.0001). Change between 36-48 was not significant 1.0 (p=0.32) Data* 12 weeks SAS mean 8.09 (SD2.99) N=23 36 weeks SAS 9.74 (SD4.00) N=21 48 weeks SAS 10.61 (SD4.54) N=21
14. Oulu (1)	Kauhanen et al 2000 (19)	Setting: stroke unit of an university hospital Inclusion: First ever brain infarction admitted to the stroke unit Exclusion: TIA, markedly decreased levels of consciousness, previous psychiatric illnesses, central nervous system disorders or alcoholism	BI, RAND-36 physical subscale 3 months N=85 12 months N=76	No associations with decline in ADL presented	3 months BI 100 median (95% CI 100-100; range 20-100) 12 months BI 100 median (95% CI 100-100; range 30-100) RAND-36 physical subscale 3 months 46.4 (SD±31.9) 12 months 50.6 (SD±34.8) P<0.05 comparing scores 3 months with those of 12 months
15. Hartford (1)	Knauft et al 2010 (20)	Setting: Stroke unit Hartford hospital Inclusion: Acute ischemic stroke, known onset and time Excluded: TIA, stroke rule-out, hemorrhagic	BI 3 months N= 812 12 months N= 812	No associations with decline in ADL presented	Data* 3 months BI mean 17.3(SD0.5) men 3 hours, 15.5(SD0.6) women 3 hours 12 months BI mean 17.5(SD0.5) men 3 hours, 16.4(SD0.5) women 3hours 3 months BI mean 17.6 (SD0.4) men 6 hours, 15.5(SD0.5) women 6 hours 12 months BI mean 17.7(SD0.5) men 6 hours, 16.5(SD0.6) women 6 hours

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
16. Tan Tock Seng (4)	Kong et al 2013 (21)	Setting: rehabilitation center of Tan Tock Seng Hospital Singapore (12 months) Inclusion: Presence of first ever stroke confirmed with CT/MRI Exclusion: recurrent stroke, not complete rehabilitation programme, premorbid modified rankin scale of ≥ 2	mBI 3 months N=163, 6 months N=157, 12 months N= 148	No associations with decline in ADL No associations with decline in ADL presented	3 months mBI mean 83.9 (SD19.8) 6 months mean 88.8 (SD17.2) 12 months mean 91.1 (SD15.7) Improvements in all intervals are significant (3 vs 6 months and 6 vs 12 months) (p<0.001)
17. Helsingki (1)	Kotila et al 1984 (22)	Setting: University central hospital of Helsingki and regional hospitals of the district Espoo and Kaumainen (1978-1980) Inclusion: new stroke cases	Grading system: fully independent in ADL, needs some help, needs much help, totally disabled ADL: ambulation, self-feeding, dressing and personal hygiene. Measures 3 and 12 months N=154	No associations with decline in ADL presented	3 months 95/154 (62%) independent, 12 months 105/154(68%) independent
18. Prince of Wales (1)	Lo et al 2008 (23)	Setting: Prince of Wales university Hospital (2 year period) Inclusion: Ethnic Chinese first disabling stroke, Exclusion: patients with a moderate or severe premorbid handicap level mRS score >2, recurrent stroke during follow-up time, lived to far from the hospital, life expectancy < 6months	BI, LHS subdomain mobility and independence 3 months N= 303, 6 months N=297 (N=296 for LHS), 12 months N=268	No associations with decline in ADL presented	BI: 3 months score BI median 19 (IQR 15-20) 6 months change score median 0 (IQR 0-0) 12 months change score median 0 (IQR 0-1) LHS mobility 3 months median 3 (IQR 1,3) 6 months change score median 0 (IQR 0,0) 12 months change score median 0 (IQR -1,0) LHS independence 3 months median 3 (IQR 2,4) 6 months change score median 0 (IQR 0,0) 12 months change score median 0 (IQR 0,0) BI improved from 3 to 12 months (p<0.05), no significant change from 3 to 6 months LHS mobility score improved from 3 to 12 months (p<0.005), no significant change 3 to 6 months LHS independence score not significant 3 to 12 months and 3 to 6 months

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
19. CONOCES (1)	Mar et al 2015 (24)	Setting: CONOCES-study, 19 Spanish stroke units (2010-2011) Inclusion: > 18 years of age, confirmed clinical diagnosis of first ischaemic or haemorrhagic stroke within 24 hours of onset, admission to stroke unit, voluntary participation and signed informed consent	BI 3 months N=287 12 months N=271	No associations with decline in ADL presented	3 months mean BI 77.08 (SD±32.11)* 12 months mean BI 80.56 (SD±30.11)*
20. Fortaleza (1)	Medeiros et al 2011 (25)	Setting: inpatient care Inclusion: clinical diagnosis of ischaemic stroke and age between 45 and 80 years. Exclusion: loss of ability to communicate, dementia, stupor or coma, cancer, severe lung, hepatic or renal diseases or unwillingness to participate in the study	BI 3 and 12 months N=62	No associations with decline in ADL presented	Article: 3 months with RLS mean 72.27 (SD±32.50) without RLS mean 83.09 (SD±23.16) 12 months with RLS mean 84.50 (SD±25.26), without RLS mean 91.21 (SD±20.02) Total group: 3 months BI mean 81.17 (SD±25.01) 12 months BI mean 90.02 (SD±20.97)
21. CERISE (1)	Meyer et al 2015 (26)	Setting: CERISE-study 4 rehabilitation centers in Europe (2008-2009)	BI	No associations with decline in ADL presented	Mean change score 6 months -5 years -6,6 (SD1.54). Significant decline between 6 months and 5 years
22. Soderstalje (1)	Nydevik et al 1992 (27)	Setting: Soderstalje hospital Sweden (1986-1987) Inclusion: acute stroke symptoms persisting more than 24 hours	SIP physical domain (consisted SIP ambulation, SIP mobility and SIP body care and movement) Higher scores means higher sickness impact 6-9 months and 3 years post stroke N=36	Dependent/independent significant difference in mean change in domain SIP body care and movement in favour of the dependent persons(declined function). Independent declined in the score domain body care and movement (improved function). No significant difference between men and woman, between patients living alone or together, left or right symptoms or age on long-term changes.	6-9 months: SIP ambulation median 18.2; SIP body care and movement median 6.2 3 years SIP phys median 15.3 SIP ambulation 28.1 SIP mobility 24.6 SIP BCM 8.1 Mean difference SIPA 4.6 (95%CI 0.5-8.7) SIPBCM 4.5 (95%CI 0.3-8.7)

Table III. (Continued)

Study number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
23. POSTGOT (1)	Persson et al 2014 (28)	Setting: POSTGOT- study. Stroke unit Sahlgrenska university Hospital. Inclusion: first ever stroke according to WHO criteria. Exclusion: comorbidities such as leg amputation, a diagnosis of dementia or severe psychiatric diseases that could interfere with mobility or the ability to cooperate during the assessments.	TUG 3 months N=77, 6 months N=71, 12 months N=70	Age >80 tended to deteriorate from 3 to 12 months (p<0.05) Time after stroke, age group (45-64, 65-79 and over 80) and the interaction of these two factors were used as fixed explanatory variables	3 months TUG mean 14.5 (SD10.0) Median 11.9 (IQR10.0-16.3) 6 months TUG mean 14.2 (SD9.4), Median 11.5 (10.0-16.0) 12 months TUG mean 14.7 (SD9.8), Median 12.0 (9.0-17.0) 3 to 6 months 41% improved, 32% unchanged, 27% deteriorated 6 to 12 months 36% improved, 22% unchanged, 40% deteriorated (2% unknown) Change between 3-6 months non-significant Change between 6-12 months non-significant Change between 3-12 months non-significant (p=0.90)**
24. Amrita (1)	Pillai et al 2007(29)	Setting: Amrita institute of medical science a tertiary care university teaching hospital (2001-2004) Inclusion: patients presenting acute MCA infarction <65 years, GCS score <14 non-dominant hemisphere or <9 dominant hemisphere, no signs of herniation or brainstem reflexes, operative risk acceptable regarding other major comorbidities, decompressive hemi-cranectomy	BI, FIM walking 6 months N=17, 12 months N=18	No associations with decline in ADL presented	6 months BI mean 80.0 (SD±21.9) 12 months BI mean 80.6 (SD±24.4) 6 months FIM walking mean 5.5 (SD1.74) 12 months FIM walking mean 6.1 (SD1.70)

Table III. (Continued)

Study number of publications	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
25. Nacka (1)	Skåner et al 2007 (30)	Setting: Nacka centre for family and community medicine (1999-2001) Inclusion: first ever stroke according to WHO Exclusion: TIA, SAH	KATZ ADL index 3 months N=145, 12 months N=135	No associations with decline in ADL presented	ADL CATEGORY 3 vs 12 A 98 (67.6%) vs 92 (68.1%) B 14 (9.6%) vs 13 (9.6%) C 5 (3.4%) vs 9 (6.7%) D 2 (1.4%) vs 4 (3.0%) E 11 (7.6%) vs 7 (5.2%) F 11 (7.6%) vs 8 (5.9%) G 4 (2.8%) vs 1 (0.7%) After 12 months, no patients in a higher ADL category compared with three months, 104 patients in the same (72%), 31 patients (21%) declined and 10 (7%) died. Data* 3 months KATZ 4.945 (SD1.836) N=145 12, months KATZ 5.127 (SD1.577) N=135
26. Adelaide (1)	Smith et al 1995 (31)	Setting: Rehabilitation unit of repatriation general hospital Adelaide (1986-1988) Inclusion: All stroke patient Exclusion: poor understanding of language, required to another unit for more than 1 week, cognitive deficiency MIMST<21, previous stroke, suffered extensions to their stroke while in rehabilitation	Australian ADL index 6 and 12 months N=98	Competence: Decline in ADL was unrelated to sex, marital status of the patient and side of lesion (not mentioned at which time point). Change occurred during time spent in rehabilitation (<6 months). Performance: The effect of time was unrelated to side of lesion. Factors used: sex, marital status, side of lesion.	Competence 6 months mean 19.7 (SD5.0, range 17-40, 95%limits 18.7-20.7) 12 months mean 19.6 (SD5.4, range 17-45, 95%limits 18.5-20.7) Performance 6 months mean 20.7 (SD6.2, range 17-47, 95%limits 19.5-21.9) 12 months mean 21.0 (SD7.2 range 17-48, 95%limits 19.6-22.4) There was no significant change in ADL performance scores between 6 -12 months.
27. NEMESIS (1)	Sturm et al 2002 (32)	Setting: NEMESIS(1996-1997) Inclusion: first ever stroke according to WHO definition, resident within the region of the study, event have been detected and diagnosed by a medical practitioner within 28 days Exclusion: SAH	BI 3 months N=113, 12 months N=107	No associations with decline in ADL presented	BI 3 months mean score 15 % disabled (<20 points) 59 (95% CI 54-64) BI 12 months mean score 16 % disabled (<20 points) 51 (95% CI 47-56)

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
28. FuPro (4)	Schepers et al 2008 (33)	Setting: FuPro Study, Four Dutch rehabilitation centers Inclusion: admittance for inpatient rehabilitation, first-ever stroke due to CI or ICH, one-sided supratentorial lesion, >18 years Exclusion: disabling co-morbidity pre stroke BI <18, inability to speak Dutch	BI Baseline N=274, One year N=234	No associations with decline in ADL presented	CI: 12-26 weeks BI 1.54(SE0.20, P=0.00) 26-52 weeks BI 0.002 (SE0.14, P=0.99) ICH 12-26 weeks BI 0.48(SE0.36, P=0.19) 26-52 weeks BI 0.62 (SE0.33, P=0.06) BI showed a significant increase over time until 26 weeks, IC until 10 weeks post-stroke Data* BI 12 weeks 16.56 (SD 4.18) N=275 BI 26 weeks 17.65 (SD 3.14) N=294 BI 52 weeks 17.98 (SD 2.89) N=268
	Schepers et al 2006 (34)	Setting: FuPro Study, Four Dutch rehabilitation centers Inclusion: admittance for inpatient rehabilitation, first-ever stroke due to CI or ICH, one-sided supratentorial lesion, >18 years Exclusion: disabling co-morbidity pre stroke BI <18, inability to speak Dutch	BI, FIM motor, SA-SIP30 Physical N=163 all measurement points Decrease of SA-Sip30 score means improvement in function	No associations with decline in ADL presented	BI 6 months 18.7 (1.6) range 13-20 IQR 18-20 BI 12 months 18.9 (1.5) range 14-20 IQR 18-20 FIM motor 6 months 111.7 (SD8.3) range 81-124 IQR 107-118 FIM motor 12 months 112.2 (SD8.3) range 83-125 IQR 109-119 SA-SIP30 physical 6months 29.9(SD20.8) range 0-90.9 IQR 18.2-45.5 SA-SIP30 physical 12 months 26.7 (SD20.5) range 0-100 IQR9.1-36.4
	van de Port et al 2006 (35)	Setting: FuPro Study four rehabilitation centers in the Netherlands Inclusion: age >18, first ever stroke according to WHO and a supratentorial lesion located on 1 side. Exclusion: prestroke BI <18 and insufficient command of Dutch	RMI 1 year post stroke, N=264, three years post stroke N=205	Univariate analysis mobility decline: impaired motor function of the leg, adl dependency, inactive level of activity, impaired cognitive function, presence of depression, presence of fatigue and living alone Multivariate logistic regression analysis on mobility decline: level of activity, cognitive problems, fatigue and depression at 1 year after stroke.	The Wilcoxon signed rank test showed a statistically significant decrease in RMI score between 1 and 3 years (z=-4.58; P<0.05) RMI change score between 1-3 years (-12-+4) median on both timelab 13 (IQR 3) Decline in 43 patients(21%), maintained 146 (72%) and 13 (7%) improved. Data* RMI 1 year 12.03 (SD3.37) N=259 RMI 3 years 11.64 (SD3.26) N=217

Table III. (Continued)

Study (number of publications)	Authors, year	Design and population	Outcome measures and time points after stroke	Associations with decline in ADL	Analysis and results
Van Wijk et al 2006 (36)		<p>Setting: FuPro Study</p> <p>Inclusion criteria: > 18 years, first ever stroke, supratentorial 1- sided</p> <p>Exclusion: other invalidating diseases that influenced daily functioning prior to admission for stroke (Bis18)</p>	<p>RMI</p> <p>1 and 2 years after stroke N=148</p>	<p>Univariate regression analysis</p> <p>mobility decline: Depression (OR 4.2 95%CI 1.3-13.2)</p> <p>Multivariate analysis was not an issue</p> <p>Non-significant factors : age (>65 vs ≤65), sitting balance (TCT score <25 vs ≥35), aphasia (token test score ≥9 vs <9), cognitive dysfunction (MMSE≤23), Depression (CES-D ≥16), fatigue (FSS ≥5) and poor social functioning (FAI<19)</p>	<p>The Wilcoxon signed rank test showed a no significant difference between 1 and 2 years (P=0.27)</p> <p>RMI 1 year median 13 (IQR 12-14)</p> <p>RMI 2 years median 13 (IQR 11-14)</p> <p>Decline in 12.2% of patients, improved 6.9% and 79.9% maintained</p> <p>Data *</p> <p>RMI 1 year mean 12.37 (SD2.89) (n=147)</p> <p>RMI 2 years mean 12.28 (SD 2.74)</p> <p>BI 1 year mean 18.25 (SD 2.40)</p> <p>BI 2 years mean 18.14 (SD2.52)</p>

*Data shared after request by mail

P-ADL= Personal Activities of daily living, I-ADL= instrumental activities of daily living, SLSR= South London Stroke Register, WHO= World Health Organization, BI= Barthel Index, SD= Standard Deviation, TIA= Trans Ischemic Attack, CI= confidence interval, SE=Standard Error , RMAGF=Rivermead Motor Assessment Gross Motor Function, TMWT= Ten Meter Walk Test, IQR= Inter Quartile Range, CVA= Cerebro Vascular Accident, SF-36 PF= Short Form Health Survey 36 Physical Functioning, NOMASS= Northern Manhattan Stroke Study, OR= Odds Ratio, BADL= Basic Activities of Daily living, FIM=Functional Independence Measurement, UMC= Universal Medical Center, QoL= Quality of Life, SIS= Stroke impact scale, LHS= London Handicap Scale, SAS= Symptom Assessment Scale, RAND=Research and Development, CT/MRI= Computer Topography/Magnetic Resonance Imaging, mBI= Modified Barthel Index, mRS= Modified Ranking Scale, RLS= Restless Leg Syndrome, SIP= Sickness Impact Profile, TUG= Time up and Go, MCA= Middle Cerebral Artery, SAH Subarachnoid Haemorrhage, MMST= Mini Mental State Test, ICH= Intracerebral Haemorrhage, NEMESIS= North East Melbourne stroke Incidence study, FuPro= Functional Prognosis, RMI= Rivermead mobility index

Table VI. Risk of Bias and Methodological quality of included studies

Study	Author	Risk of Bias Study Participation	Study Attrition	Prognostic factor measurement	Outcome Measurement	Statistical Analysis and Reporting	Quality publication Total score
1. Orebro	Appelros et al 2005 (1)	Moderate	Moderate	Low	Moderate	Low	High
2. SLSR 1	Samuelsson et al 1996 (2)	Low	Moderate	High	Moderate	High	Low
	Taub et al 1994 (3)	Low	High	Low	Moderate	Low	Low
	Wilkinson et al 1997 (4)	Moderate	High	Low	Moderate	Moderate	Low
3. SLSR 2	Tilling et al 2001 (5)	Low	Moderate	Moderate	Low	Low	High
	Ayerbe et al 2011 (6)	Low	High	Low	Low	Low	Low
4. SLSR 3	Wolfe et al 2011 (7)	Low	High	Low	Low	Moderate	Low
	Toschke et al 2010 (8)	Low	Moderate	Low	Low	Moderate	High
5. Leuven	Baert et al (9)	Moderate	High	Low	Low	Moderate	Low
6. Midwestern Medical center	Callahan et al 2005 (10)	High	High	N.A.	Low	High	Low
	Dhamoon et al 2009 (11)	Low	Moderate	Low	Low	Moderate	High
7. NOMASS	Willey et al 2010 (12)	Low	High	High	Moderate	Moderate	Low
	Fukuda et al 2009 (13)	Low	High	Low	Low	Low	Low
8. Kitasato	Gbiri et al 2012 (14)	Moderate	Moderate	High	High	High	Low
9. Ibadan	Gosman et al 2004 (15)	Low	Moderate	N.A.	Low	High	Low
	Hamza et al 2014 (16)	Low	Moderate	Low	Low	Low	High
11. Kano	Harwood et al 1997 (17)	Moderate	Moderate	Moderate	Low	Low	High
	Horgan et al 2009 (18)	Moderate	Low	N.A.	Low	Low	High
13. Dublin	Kauhanen et al 2000 (19)	Low	Moderate	Low	Low	Moderate	High
	Knauff et al 2010 (20)	Moderate	High	Low	Low	Moderate	Low
15. Hartford	Kong et al 2013 (21)	Low	Moderate	Low	Low	Low	High
	Kotila et al 1984 (22)	Low	Moderate	Moderate	Moderate	Moderate	High
17. Helsinki	Lo et al 2008 (23)	Low	Moderate	Low	Low	Low	High
	Mar et al 2015 (24)	Low	Low	Low	Low	Low	High
18. Prince of Wales	Medeiros et al 2011 (25)	Low	High	Moderate	Moderate	Moderate	Low
19. CONOCES	Meyer et al 2015 (26)	Low	Moderate	Low	Low	Low	High
20. Fortaleza							
21. CERISE							

Table VI. (Continued)

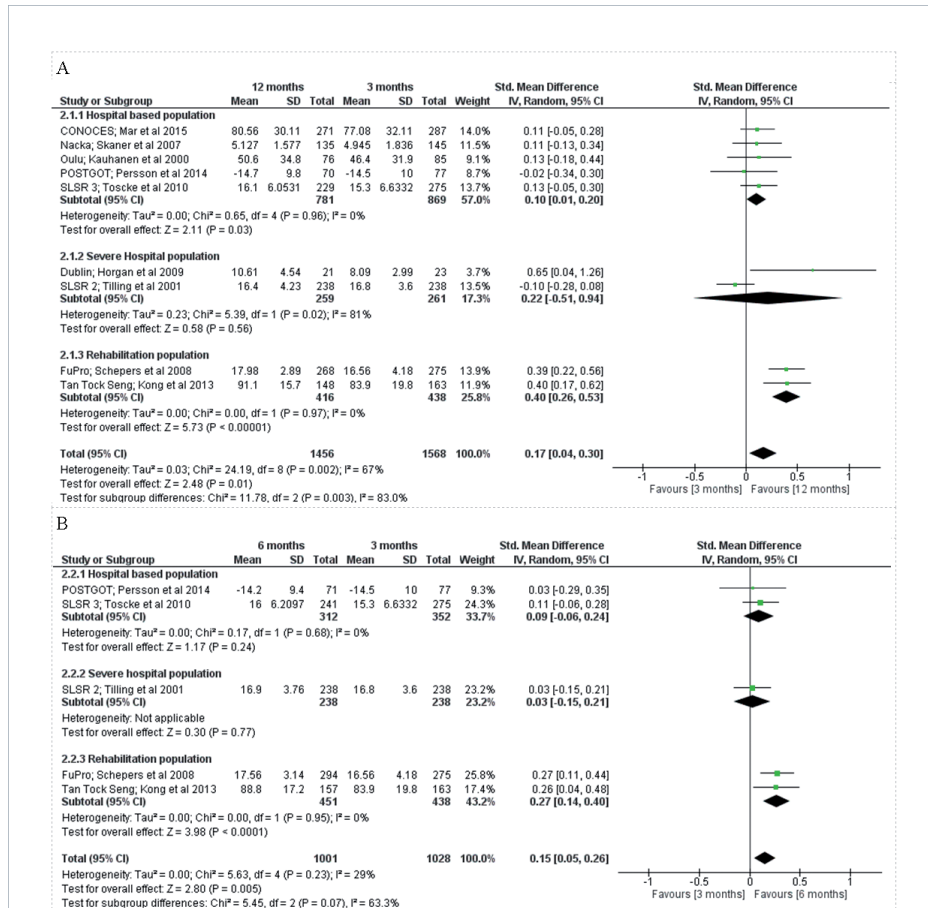
Study	Author	Risk of Bias Study Participation	Study Attrition	Prognostic factor measurement	Outcome Measurement	Statistical Analysis and Reporting	Quality publication Total score
22. Soderstalje	Nydevik et al 1992 (27)	Moderate	High	Moderate	Low	Low	Low
23. POSTGOT	Persson et al 2014 (28)	Low	Moderate	Low	Low	Low	High
24. Amrita	Pillai et al 2007 (29)	Moderate	Moderate	High	Moderate	High	Low
25. Nacka	Skaner et al 2007 (30)	Low	Moderate	N.A.	Low	Moderate	High
26. Adelaide	Smith et al 1995 (31)	Low	Moderate	Low	Low	Low	High
27. NEMESIS	Sturm et al 2002 (32)	Low	Low	Low	Low	Low	High
28. FuPro	Schepers et al 2008 (33)	Moderate	Moderate	Low	Low	Low	High
	Schepers et al 2006 (34)	Moderate	High	N.A.	Low	Low	Low
	van de Port et al 2006 (35)	Low	Moderate	Low	Low	Low	High
	van Wijk et al 2006 (36)	Low	High	Low	Low	Moderate	Low

N.A.: not applicable

Table V. Pooling course of ADL

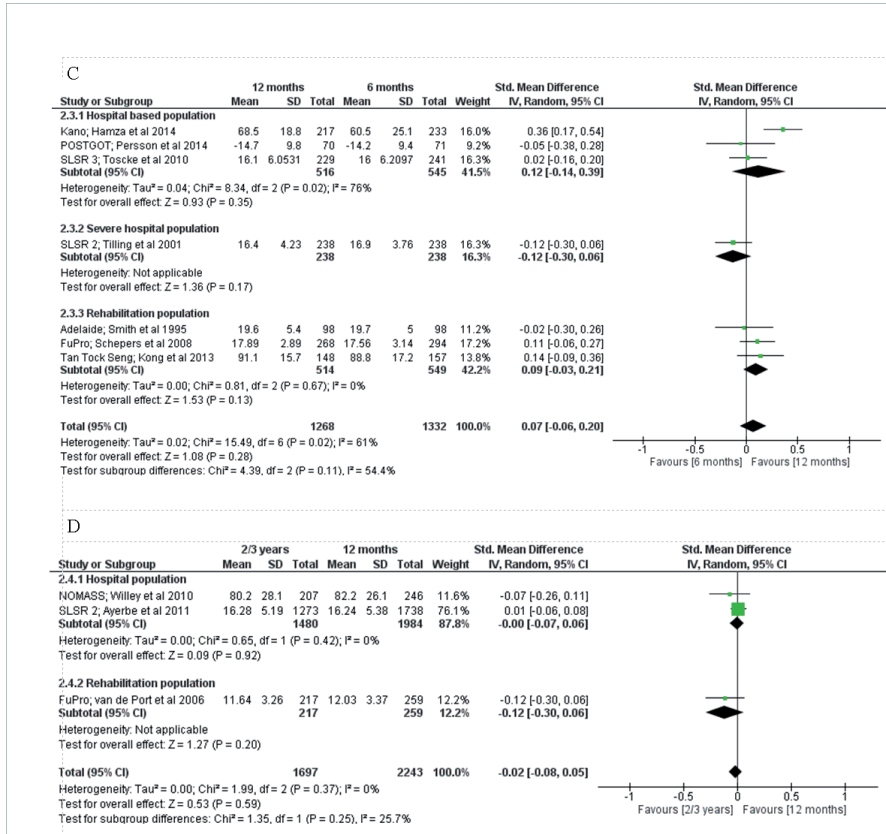
Course	Quality of publications	Number of studies	Number of subjects (baseline/follow-up)	Std Mean Difference	95%CI	P-value	Heterogeneity (I ²)
3-12 months	High	9 (5,8,18,19,21,24,28,30,33)	1568/1456	0.17	0.04,0.30	P<0.05	67%
	High and low	13(6,8,9,14,18-21,24,25,28,30,33)	4300/4114	0.45	0.23,0.67	P<0.01	95%
3-6 months	High	5 (5,8,21,28,33)	1028/1001	0.15	0.05,0.26	P<0.05	29%
	High and low	7 (5,8,9,14,21,28,33)	1115/1087	0.37	0.05,0.68	P<0.05	92%
6-12 months high/low quality studies	High	7 (5,8,16,21,28,31,33)	1332/1268	0.07	0.06,0.20	P=0.28	61%
	High and low	11 (5,8-10,14,16,28,29,31,33)	1603/1440	0.11	0.02,0.25	P=0.10	67%
12> months		3 (6,12,35)	2243/1697	-0.02	0.08,0.05	P=0.59	0%

Std= standardized, CI= confidence interval



Appendix Figure IA. Standardized mean difference of the course of activities of daily living with subgroup analyses place of recruitment between 3 and 12 months (A), 3 and 6 months (B). A positive mean difference score indicates an improvement in activities of daily living-function.

Std.= standardized, SD=standard deviation, CI= confidence interval, I²= Heterogeneity



2

Appendix Figure IB. Standardized mean difference of the course of activities of daily living with subgroup analyses place of recruitment between 6 and 12 months (C), 12 months and 2/3 years (D). A positive mean difference score indicates an improvement in activities of daily living-function. Std.= standardized, SD=standard deviation, CI= confidence interval, I²= Heterogeneity

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CHAPTER 3



VALIDATION AND RESPONSIVENESS OF THE LATE-LIFE FUNCTION AND DISABILITY INSTRUMENT COMPUTERIZED ADAPTIVE TEST IN COMMUNITY-DWELLING STROKE SURVIVORS

Roderick Wondergem

Martijn F. Pisters

Eveline J.M. Wouters

Rob A. de Bie

Johanna M.A. Visser-Meily

Cindy Veenhof

Abstract

Background

Follow-up of stroke survivors is important to objectify activity limitations and/or participation restrictions. Responsive measurement tools are needed with a low burden for professionals and patients.

Aim

To examine the concurrent validity, floor, and ceiling effects and responsiveness of both domains of the Late-Life Function and Disability Index Computerized Adaptive Test (LLFDI-CAT) in first-ever stroke survivors discharged to their home setting.

Design

Longitudinal Study

Setting

Community

Population

First-ever stroke survivors

Method

Participants were visited within three weeks after discharge and six months later. Stroke impact scale (SIS 3.0) and five-meter walk test (5MWT) outcomes were used to investigate concurrent validity of both domains, activity limitations, and participation restriction, of the LLFDI-CAT. Scores at three weeks and six months were used to examine floor and ceiling effects, and change scores were used for responsiveness. Responsiveness was assessed using predefined hypotheses. Hypotheses regarding the correlations with change scores of related measures, unrelated measures, and differences between groups were formulated.

Results

105 participants were evaluated. Concurrent validity (R) of the LLFDI-CAT activity limitations domain compared with the physical function domain of the SIS 3.0 and with the 5MWT was 0.79 and -0.46, respectively. R of the LLFDI-CAT participation restriction domain compared with the participations domain of the SIS 3.0 and with the 5MWT was 0.79 and -0.41, respectively. A ceiling effect (15%) for the participation restriction domain was found at six months. Both domains, activity limitations and participation restrictions, of the LLFDI-CAT, scored well on responsiveness: 100% (12/12) and 91% (12/11) respectively of the predefined hypotheses were confirmed.

Conclusions

The LLFDI-CAT seems to be a valid instrument, and both domains are able to detect change over time. Therefore, the LLFDI-CAT is a promising tool to use both in practice and in research.

Clinical rehabilitation impact

The LLFDI-CAT can be used in research and clinical practice.

Introduction

The majority of people with stroke will return to the home setting after their first-ever stroke¹. Over forty percent of the population reports limitation in activities of daily living (ADL), and a substantial part of the population reports restrictions in participation compared with life before a stroke². Furthermore, a substantial part of people with stroke decline in ADL is observed within the first three years after a first-ever stroke³. Less attention has been paid to the long-term burden of stroke, and in practice, most stroke patients have no longer contact with healthcare professionals⁴. To provide recommendations for adequate follow-up after a stroke, a measurement tool focusing on ADL and participation that is sensitive to change and with a low burden for patients is needed.

Many instruments have been developed to assess activity limitations and participation restrictions in people with stroke. However, these instruments have several disadvantages. The most used tool to measure activity is the Barthel Index (BI). However, the BI has a large ceiling effect^{5,6}. Another commonly used tool, the modified Rankin Scale (mRS), only gives a global impression of mainly activities⁵. Patient-reported outcomes measures (PROMs) provide additional valuable information⁷. However, PROMs like the Stroke Impact Scale (SIS) and Utrecht Scale for Evaluation of Rehabilitation-Participation are fixed forms, whereas some questions are not applicable for individual patients and time-consuming to fill-out for patients and/or professionals^{8,9}. Due to potential cognitive problems and lower energy levels in patients after stroke, it is essential to have simple PROMs with low administrative burdens.

The limitations mentioned can be overcome by using a Computerized Adaptive Testing (CAT) PROM. CAT instruments have several advantages over conventional instruments¹⁰. CAT-instruments use the response to an initial question to select the subsequent question. Irrelevant, too easy, or too difficult questions for the individual are skipped. Thence, CAT instruments reduce the number of questions needed, maintain measurement precision, and decrease the respondent burden.

A promising CAT PROM is the Long-Life Function and Disability Instrument – CAT version (LLFDI-CAT)¹¹. The LLFDI-CAT was developed and validated within gerontology research¹² and measures two domains, activity limitations and participation restrictions¹¹. The terms of the two domains are based on the International Classification of Functioning, Disability, and Health (ICF)^{13,14}. The LLFDI-CAT has a database with 137 questions in the activity limitation domain and 55 in the participation domain. Questions are selected based on the answer given to the previous question. The instrument is completed after reaching a predefined stopping rule. The LLFDI-CAT contains two stopping rules that can be adjusted based on the purpose of use: 1) the number of questions; 2) reaching the predefined standard error of measurement (SEM) of 3.0¹¹. Both the English version and Dutch translation showed promising psychometric results in community-dwelling older persons^{11,15}. Also, the LLFDI-CAT has shown validity in chronic disease population¹⁶ and seems to be sensitive to measure change¹².

Due to the broad scope of the LLFDI-CAT on both activity and participation domain, it might be useful for community-dwelling stroke patients. However, before using this PROM in a stroke population, both concurrent validity and responsiveness need to be evaluated. Therefore, the purpose of this study was to; 1) investigate the concurrent validity of the activity limitation and the participation restriction domain of the LLFDI-CAT; 2) identify floor and ceiling effects, and 3) examine the responsiveness in community-dwelling stroke patients¹⁷.

Methods

Study population

This study was conducted following the recommendations of the statement Standards for Reporting of Diagnostic Accuracy Studies. Data from the RISE-study, a two-year hospital cohort study on physical behavior, functional decline, and recurrent events in community-dwelling people with stroke, was analyzed. Participants were included between February 2015 and May 2016. Eligible participants were recruited from four participating hospitals in The Netherlands. Inclusion criteria were: 1) having a clinically confirmed first-ever stroke; 2) being discharged from inpatient care (hospital or inpatient rehabilitation) to the home setting; 3) independent in ADL before stroke (BI score >18)¹⁸; 4) age over eighteen. Exclusion criteria were: 1) scores below four on the Utrecht Communication Assessment¹⁹; 2) not able to walk without supervision (<3 on the Functional Ambulation Categories²⁰), and 3) insufficient Dutch-speaking and reading skills.

Eligible patients were asked to participate in the study by their health care professionals in the stroke unit. Informed consent was obtained from all individual participants included in the study. Participants gave their written consent to provide contact details, stroke characteristics, and patient characteristics to the researcher. Data collection was performed by participants at home within three weeks and six months later, after discharge. Prior to the data collection at the participants' home, participants received a postal questionnaire. The study was approved by the Medical Ethics Committee of the University Medical Centre Utrecht, the Netherlands (NL14-076).

Assessment of Validity

To determine the concurrent validity of the LFDI-CAT, the Stroke impact scale 3.0 (SIS) and five-meter walking test (5MWT) were used.

Assessment of Responsiveness

Responsiveness is the ability of an instrument to detect changes over time in the construct to be measured¹⁷. Hypotheses regarding the correlations with the change scores of related measures (convergent validity), unrelated measures (discriminant validity), and the differences between groups (discriminative validity) were formulated^{17,21}. The SIS 3.0 domain's physical functioning and participation were used because these subscales are measuring the same construct according to the International Classification of Functioning, disability, and Health (ICF) as the domains of the LFDI-CAT. Because the included population was discharged to the community after acute care or after rehabilitation care, this population would mainly have mild to moderate stroke symptoms in the Netherlands²². The SIS is able to measure change over time in a mild to moderate stroke population^{23,24}. Additional

a measurement tool that was able to measure both activity limitations as participation restrictions were needed. To limit the burden for the patient, only one measurement tool was chosen. Walking speed is associated with both activity limitations and participation restrictions^{15,25}. Because it was not possible to perform the 10 MWT in some residences, the 5MWT was chosen. Additionally, the 5MWT shows the same psychometric proportions compared to the 10 MWT²⁶. The Hospital Anxiety and Depression scale, self-efficacy for symptom management scale and checklist individual strength – fatigue are commonly used, valid, and reliable tools and are measuring different constructs according to the ICF as compared with the LLFDI-CAT domains¹⁴. Although some of these measurement tools are correlated with activity and participations domains³, we assumed that the correlation of the changes scores wouldn't exceed 0.3. Therefore, these instruments were used to assess discriminant validity. Three consecutive steps were followed to formulate hypotheses: 1) The principal investigator formulated hypotheses based on literature; 2) a group of five experts was formed and gave individual written feedback on the hypotheses; 3) in case of no consensus, a group meeting was planned to reach consensus. Table 1 presents the formulated hypotheses.

Patient- and stroke characteristics

Patient characteristics that were collected were age, sex, and living alone or together. Stroke characteristics provided information on stroke severity, type (hemorrhage or infarction), hemisphere, and location. Stroke severity was assessed using the National Institutes of Health Stroke Scale (NIHSS)²⁷. The NIHSS measures stroke severity by using eleven items. For each item, a zero score means normal function, a score above zero is indicative for some level of impairment. Scores are summed up with a maximum score of 42 and the minimum score of zero. In this cohort, three categories were used 1) no stroke symptoms (0 points); 2) minor stroke (1-4 points); 3) moderate to severe stroke (≥ 5 points)²⁷. The NIHSS has shown excellent reliability and validity^{28,29}.

Long-Life Function and Disability Instrument-Computer adaptive test version

The LLFDI-CAT is a PROM consisting of a large item bank for both domains. Items were calibrated on a scale ranging from 0 to 100, with a mean of 50.¹¹ A higher score indicates fewer activity limitations and fewer participation restrictions. The standard question asked within the activity limitation domain is: *“How much difficulty do you currently have doing..?”* supplemented with a particular activity. The participants were allowed to answer *“no difficulty; a little difficulty; a lot of difficulties; unable to do; and does not apply”*. For the participation restriction domain, the question: *“Because of your physical or mental health, to what extent do you feel limited in doing..?”* is asked, supplemented with a particular activity. Again five answers can be given: *“not limited at all; a little limited; a lot limited; completely limited; and does not apply”*. Per answer, the software calculates a participant score and an

SEM. The final participants' score and level of SEM are calculated after reaching one of the stopping rules. In the present study, the instrument stopped after 10 questions per domain or when the patient-level SEM was less than 3.0.

Comparative assessment tools

The Stroke Impact Scale 3.0

The SIS is a PROM designed to measure perceived functional status. Subscales can be evaluated separately. The following subscales of the SIS 3.0 were used: 1) Physical (including ADL/iADL, mobility, hand function); 2) Participation; and 3) Perceived overall recovery. The physical subscale contains twenty-four questions, the participation subscale eight questions. Both subscales show excellent validity, reliability, and responsiveness²⁴. Per subscale, the scores were calculated as a percentage of the total score, in which a higher score indicates better physical ability or higher participation levels. Perceived overall recovery was assessed to measure the patient's perception of stroke recovery. Patients were asked, "how much have you recovered from your stroke?" with zero representing no recovery and one hundred representing full recovery.

Five-meter walking test

The 5MWT was used to measure walking speed. Participants were asked to walk three times, five meters at a comfortable speed. The average of the three attempts was calculated. The 5MWT is a reliable and valid tool^{26,30}.

Anxiety and Depression

The Hospital anxiety and depression scale (HADS) determines symptoms of anxiety and depression. The HADS consists of fourteen items; seven about anxiety and seven about depression. Each question has a 4-point rating scale⁰⁻³, where higher scores indicate higher levels of anxiety or depression. The HADS is a reliable and valid tool^{31,32}.

Fatigue

The Checklist individual strength - fatigue (CIS-f) assesses the amount of fatigue. CIS-f consists of eight items. Each item can be rated on a seven-point Likert-scale (range 8-56). A score of 8 is considered to reflect low amounts of fatigue, and 56 reflects high amounts of fatigue. The CIS-f has proven reliability and validity³³.

Self-efficacy

Self-efficacy was evaluated with the self-efficacy for symptom management scale (SESx). The SESx consists of 13 items with a range score of 13-130, whereas a high score indicates a higher level of self-efficacy. The SESx is a reliable and valid tool³⁴.

Table 1. Predefined hypotheses to assesses the responsiveness of the LLFDI-CAT activity limitations and participation restrictions domain.

Hypotheses LLFDI-CAT activity limitations	Hypotheses LLFDI-CAT participation restrictions
Convergent	Convergent
There is at least a correlation >0.3 between Δ LLFDI activity limitations and:	There is at least a correlation >0.3 between Δ LLFDI participation restrictions and:
<ol style="list-style-type: none"> 1. Δ domain physical functioning of the SIS 2. Δ domain participation of the SIS 3. Correlation of physical functioning domain > participation of the SIS 4. Δ domain perceived recovery of the SIS 5. Δ 5MWT 	<ol style="list-style-type: none"> 1. Δ domain participation of the SIS 2. Δ domain physical functioning of the SIS 3. Correlation of participation domain > physical functioning domain of the SIS 4. Δ domain perceived recovery of the SIS 5. Δ 5MWT
Discriminant	Discriminant
There is a correlation ≤ 0.3 between Δ LLFDI activity limitations and:	There is a correlation ≤ 0.3 between Δ LLFDI participations restrictions and:
<ol style="list-style-type: none"> 6. Δ self-efficacy 7. Δ anxiety 8. Δ depression 9. Δ fatigue 	<ol style="list-style-type: none"> 6. Δ self-efficacy 7. Δ anxiety 8. Δ depression 9. Δ fatigue
Discriminative	Discriminative
<ol style="list-style-type: none"> 10. The ability to distinguish patients improved and those who remain stable or 10. The ability to distinguish patients improved and those who remain stable improved (AUC≥ 0.7) 11. We hypothesized that participants who had inpatient rehabilitation in between 11. We hypothesized that participants who had inpatient rehabilitation in between discharge to the home setting and the hospital showed more change compared with discharge to the home setting and the hospital showed more change compared with a participant who was discharged directly to the home setting after hospital care a participant who was discharged directly to the home setting after hospital care 12. We hypothesized that participants who were classified as community walkers 12. We hypothesized that participants who were classified as community walkers showed less change compared with limited community walkers 	<ol style="list-style-type: none"> 10. The ability to distinguish patients improved and those who remain stable or 10. The ability to distinguish patients improved and those who remain stable improved (AUC≥ 0.7) 11. We hypothesized that participants who had inpatient rehabilitation in between 11. We hypothesized that participants who had inpatient rehabilitation in between discharge to the home setting and the hospital showed more change compared with discharge to the home setting and the hospital showed more change compared with a participant who was discharged directly to the home setting after hospital care a participant who was discharged directly to the home setting after hospital care 12. We hypothesized that participants who were classified as community walkers 12. We hypothesized that participants who were classified as community walkers showed less change compared with limited community walkers

LLFDI-CAT = Long-Life Function and Disability Instrument-Computer adaptive testing version, SIS = Stroke impact scale 3.0, 5MWT = five meter walking test, AUC = Area under the receiver operating characteristics curve.

Statistical analysis

Data were analyzed using SPSS 21.0 (SPSS Inc., Chicago, IL, USA). Concurrent validity, floor and ceiling effects, and responsiveness were assessed following the recommendations of the COnsensus-based Standards for the selection of health status Measurement Instruments and proposed quality criteria by Terwee et al.^{17,35}. For this study, a sample of at least fifty participants is needed³⁵. Descriptive statistics were used to describe the participants' characteristics.

Concurrent validity

Concurrent validity of both domains of the LLFDI-CAT was determined by comparing scores with the SIS physical functioning subscale and the participation subscale as well as with the 5MWT respectively. Correlations were calculated. When data were non-normally distributed Spearman's rho was used, otherwise Pearson's r was used. Normality was checked by comparing histograms to a normal probability curve. The convention of Cohen for effect sizes of Pearson's r (< 0.10 small, between 0.1 and 0.3 medium and ≥ 0.5 large effect size) was used for interpretation³⁶.

Floor and ceiling effects

Floor and ceiling effects were determined of both LLFDI-CAT domains. Floor and ceiling effects were considered to be present if more than fifteen percent of the respondents achieved the lowest or highest possible score^{17,37}.

Responsiveness

The responsiveness was considered to be adequate when >75% of the predefined hypotheses were confirmed (table 1)¹⁷. The change scores of related and unrelated measures were calculated. All correlations were calculated in the same manner as the concurrent validity. Discriminative validity was calculated using the size of the area under the receiver operating characteristic curve (AUC)³⁸. The AUC measures the ability of a questionnaire that distinguishes between patients who have changed and who remained stable, according to an external criterion. We considered an AUC of at least 0.70 to be adequate¹⁷. The AUC was calculated for improvements in the activity and participation domain using the change score of the LLFDI-CAT activity limitations and participation restrictions domain. Since a gold standard for change in both domains is lacking, we used patients' perceived change of overall recovery from the SIS. A change of at least 10 percent was considered to be a clinically important change³⁹. Scores were dichotomized to indicate individual improvement vs. participants who remained stable. The dichotomized scores were used in the AUC.

Results

In total, 110 patients participated in the study, of which 105 participants (95%) completed both measurements. One participant died before the first measurement, one participant did not return the first questionnaire, and three participants were lost to follow-up. The majority of the participants were male (71,5%), the mean age at onset of stroke was 68,4 (SD 11.2) years. The majority of the population had minor stroke symptoms two days after stroke (56,2%). Twenty percent was first discharged to inpatient rehabilitation before being discharged to the home setting. The majority of the population was classified as community walkers (73,3%). The mean score at baseline was 57,36 (SD 11,54) on the LLFDI-CAT activity limitation scale and 48,38 (SD 11,38) on the LLFDI-CAT participation restriction scale. Other participants' characteristics can be found in table 2.

Table 2. Participant baseline characteristics

Characteristics N=105	% or Mean±SD
Demographic characteristics	
Males	71,45
Age (years) ^a	68,4±11,2
Living alone ^a	16,2
Stroke characteristics	
Infarction	89,5
Location	
a. cerebri anterior	2,9
a. cerebri media	57,1
a. cerebri posterior	7,6
a. vertebra basilaris	5,7
brainstem	4,8
cerebellum	8,6
lacunair	8,6
unkown	4,8
Side of stroke	
Left	53,3
Right	41,9
Both	2,9
Unknown	1,9
Stroke severity day 2 after stroke	
No symptoms (NIHSS 0)	12,4
Minor stroke symptoms (NIHSS 1 to 4)	56,2
Moderate to severe stroke symptoms (NIHSS ≥5)	31,4
Destination of discharge from hospital	
Home	80,0
Rehabilitation	11,4
Geriatric rehabilitation	8,6
Cognitive functioning ^a	24,6±3,7

Table 2. (Continued)

Characteristics N=105	% or Mean±SD
Impaired cognitive function (MOCA ≤25) ^a	38,1
Depressed	19,0
Anxiety	22,9
Walking speed (m/s) ^a	0,97±0,26
Limited community walker (≥0,93m/s) ^a	26,7
LLFDI-CAT activity limitations ^a	57,36±11,54
LLFDI-CAT participations restrictions ^a	48,38±11,38

%= percentage, SD= Standard deviation, NIHSS = National Institutes of Health Stroke Scale, MOCA= Montreal Cognitive Assessment, m/s= meters per second, LLFDI-CAT= Long Life Function and Disability Index Computer Adaptive testing

^a Assessments were carried out in the home setting of the participant within three weeks after discharge from inpatient care (hospital or inpatient rehabilitation).

Concurrent Validity

A strong correlation was found between the LLFDI-CAT activity limitations domain and SIS physical subscale (0.79) and a medium correlation with 5MWT^{0,46}. Likewise, a strong correlation was found between the LLFDI-CAT participations restriction domain and SIS participation subscale (0.79) and a medium correlation with the 5MWT^{0,41}.

Ceiling and floor effects

None of the participants scored the lowest possible score, meaning that no floor effect was found. Also, no ceiling effect was found within the activity limitation domain. A ceiling effect was found regarding the LLFDI-CAT participation restriction domain after six months. In total, sixteen participants (15%) scored the maximum amount of points.

Responsiveness

Table 3 presents the correlation coefficients between changes in both domains of the LLFDI-CAT and the change scores on related and unrelated outcome measures. Regarding related outcome measures, all hypotheses were confirmed for the LLFDI-CAT activity limitations domains and four out of five for the participation restrictions domain. The rejected hypothesis was: *there is at least a correlation >0.3 between Δ LLFDI participation restrictions and the change score of the 5MWT*. For both domains of the LLFDI-CAT, correlations below 0.3 were found with all unrelated constructs. Therefore, hypotheses 6 to 9 were confirmed. Both domains of the LLFDI-CAT showed a good ability to distinguish between improved patients and other participants with an AUC of ≥ 0.7 (figure I) (hypothesis 10). Hypotheses 11 and 12 were confirmed. Participants discharged to rehabilitation and limited community walkers showed in both domains more improvement compared with respectively discharge immediately to the home setting and community walkers (see table 4). All predefined

hypotheses regarding the LLFDI-CAT activity limitations domain were confirmed, and eleven out of twelve (91,7%) in the participation restrictions domain (see table 1).

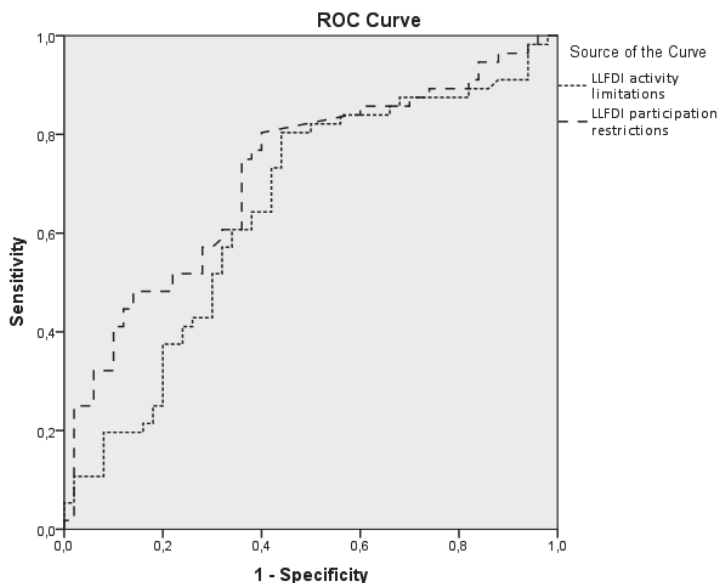


Figure I. ROC curve showing the sensitivity and 1- specificity of the activity limitations (0,7) and participation restrictions domain (0,7) of the LLFDI-CAT in patients who improved compared with the other patients.

Table 3. Pearson correlation coefficients (r, 95%) between changes scores

	Δ LLFDI activity limitations	95%CI	P- value	Δ LLFDI participation restrictions	95%CI	P-value
Δ SIS physical functioning	0,569	0,343 to 0,733	>0.001	0,483	0,236 to 0,689	>0.001
Δ SIS participation	0,407	0,210 to 0,569	>0.001	0,618	0,483 to 0,745	>0.001
Δ SIS perceived recovery	0,365	0,185 to 0,503	>0.001	0,411	0,261 to 0,549	>0.001
Δ 5MWT	0,308	0,141 to 0,451	0.001	0,262	0,111 to 0,418	0.007
Δ SESx	0,210	0,013 to 0,371	0.032	0,146	0,007 to 0,294	0.137
Δ HADS anxiety	-0,275	-0,464 to -0,090	0.005	-0,124	-0,292 to 0,046	0.207
Δ HADS depression	-0,240	-0,413 to -0,064	0.14	-0,248	-0,387 to -0,101	0.011
Δ CIS fatigue	-0,283	-0,45 to -0,097	0.003	-0,221	-0,395 to -0,031	0.024

Δ = change score, LLFDI=Long Life Function and Disability Index, CI= confidence interval, SIS= Stroke Impact Scale, 5MWT= Five Meter Walk Test, SESx= self-efficacy for symptom management scale, HADS=Hospital Anxiety and Depression questionnaire, CIS= Checklist individual strength.

Table 4. Scores three weeks after discharge, six months and change scores in total group and subgroups.

Outcome	Within three weeks after discharge mean (SD)	Six months later mean (SD)	Change Score mean (95%CI)
LLFDI activity Limitation			
Total (n=105)	57,36±11,54	59,16±9,89	1,80 (0,39 to 3,37)
Discharge to the home setting (n=84)	58,77±11,37	60,30±9,75	1,53 (-0,11 to 3,35)
Discharge to rehabilitation (n=21)	51,70±10,68	54,58±9,30	2,88 (0,86 to 4,77)
Community walkers (n=77)			
Limited or no community walkers (n=28)	46,35±10,14	49,04±6,55	2,69 (-0,46 to 5,20)
LLFDI Participation restrictions			
Total (n=105)	48,38±11,38	51,26±9,67	2,88(1,23 to 4,61)
Discharge to the home setting (n=84)	49,63±11,54	52,09±9,54	2,46 (0,62 to 4,62)
Discharge to rehabilitation (n=21)	43,38±9,40	47,93±9,65	4,55 (2,42 to 6,56)
Community walkers (n=77)			
Limited or no Community walkers (n=28)	40,59±12,70	43,52±8,99	2,94 (0,52 to 6,73)

SD= Standard Deviation, LLFDI=Long Life Function and Disability Index, SIS= Stroke Impact Scale, MWT= Meter Walk Test, SESx= self-efficacy for symptom management scale, HADS=Hospital Anxiety and Depression questionnaire, CIS= Checklist individual strength

Discussion

In this study, validity, floor and ceiling effects, and responsiveness of the LLFDI-CAT in a community-dwelling stroke population were evaluated. The study supports concurrent validity for both domains of the LLFDI-CAT. No ceiling effects were found regarding activity limitations and only a small ceiling effect six months after stroke regarding participation restrictions. The results of this study endorse that both domains of the LLFDI-CAT are able to detect changes over time. This suggests that the LLFDI-CAT is a responsive tool in community-dwelling people with stroke.

The results in this study are consistent with previous studies comparing the LLFDI-CAT domains with resembling instruments^{15,16} and with the 5 MWT^{15,40,41}. However, these studies were conducted on an elderly population. This is the first study on a stroke population. In our study, both domains of the LLFDI-CAT showed a strong correlation with the counter domains of the SIS. Both instruments are based on the same participation domain of the ICF. This could explain the high correlation between both instruments. A moderate correlation was found between the 5MWT and both domains of the LLFDI-CAT. A potential explanation is that the 5MWT only measures the physical part of disability and does not include, for example, cognitive functioning, upper extremity functioning, and environmental factors⁴².

In the activity limitations domain, no ceiling effects were found. Only a small ceiling effect was found six months after discharge from inpatient care in the participation restriction domain. Possible explanations could be that the included population in our study had mainly minor to moderate stroke symptoms and also contains young participants. Potentially these scored the highest possible score and reached the participation level as before the stroke. Another possible solution to overcome the ceiling effect is to extend the number of questions in the participation restriction domain, including higher levels of participation.

Since participation restrictions in people with stroke are common² and high on the research priority list⁴³, the LLFDI-CAT could be suggested to be used in both clinical practice and research. Additionally, the LLFDI-CAT was developed to measure over time. The results indicate the ability to measure change over time in both activity limitations and participation restrictions using the LLFDI-CAT.

Study Limitations

In a stroke population with minor to moderate stroke symptoms, the LLFDI-CAT seems a valid instrument and is able to detect change over time. Although the group discharged to a rehabilitation setting showed more change compared to the group discharged to the home setting (hypothesis 11), more research is needed to find evidence for validity and

responsiveness in a stroke population with more severe symptoms. Additionally, patients who had difficulties in speaking or languages were excluded. Aphasia is associated with worse outcome⁴⁴, and people with more severe stroke symptoms seem to be at high risk for decline in ADL³ and potential participation. Therefore, it would be interesting to investigate the agreement between caretakers and stroke survivors using the LLFDI-CAT. Concurrent validity of the LLFDI-CAT was not assessed with the BI or mRS, commonly used instruments in stroke research. It was expected that in this cohort, mainly consisting of people with minor to moderate stroke symptoms, the SIS would be more suitable to use²³. Moreover, the SIS physical functioning showed fair to good correlations with the BI and mRS^{7,24}. To investigate responsiveness, predefined hypotheses were formulated. The hypotheses remain arbitrary because there are no guidelines available. To avoid this, the same cut-off values for correlations were used as in the article of Mahler et al.⁴⁵. In the future, prescribed rules could give direction to the magnitude and amount of hypotheses to reach consensus. However, overall the results suggest the potential use of the LLFDI-CAT because it is able to measure a change in health status of relevance to the patient. Furthermore, the LLFDI-CAT could be applicable when higher precision or less precision is required because stopping rules can be adjusted if needed. This underlines the potential of the instrument.

Conclusion

The results demonstrated that the LLFDI-CAT seems to be a valid instrument and is able to detect change over time in both activity limitations and participation domain. Therefore, the LLFDI-CAT is a promising tool to use in community-dwelling stroke survivors for clinical and research purposes.

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CHAPTER 4



CRITERION AND STRUCTURAL VALIDITY OF THE ACTIV8 ACCELEROMETER IN COMMUNITY-WALKING PEOPLE WITH STROKE

Roderick Wondergem
Sanne de Kroes
Eveline J.M. Wouters
Daisy Janssen
Rob A. de Bie
Cindy Veenhof
Johanna M.A. Visser-Meily
Martijn F. Pisters

Submitted

Abstract

Aim

To determine the criterion and structural validity of the Activ8 accelerometer when assessing sedentary behavior, standing, walking, and cycling in community-walking people with stroke.

Materials and methods

The participants wore Activ8 while performing consecutive tasks using a standardized protocol. For criterion validity, output data of the Activ8 were compared with video data. Sensitivity, specificity, and positive predictive values were calculated. The structural validity of the Activ8 was investigated during daily life with the MoveMonitor as a reference accelerometer. The participants wore the devices for two days. Agreement between the Activ8 and MoveMonitor was determined using intraclass correlation coefficients (ICCs) and mean differences.

Results

Criterion validity of the Activ8 during sedentary behavior, standing, walking, and cycling was good. Sensitivity values were 91.9 for sedentary behavior, 81.9 for standing, 80.7 for walking, and 76.3 for cycling. ICC scores between the Activ8 and MoveMonitor varied between 0.76 and 0.91, indicating substantial to good structural validity in daily life.

Conclusion

The Activ8 is a valid tool for the continuous monitoring of sedentary behavior, standing, walking, and cycling in community-walking people with stroke.

Keywords

Stroke, Accelerometer, Activ8, criterion validity, structural validity.

Introduction

Little is known about actual movement behavior in daily life in people with stroke¹⁻³. Movement behavior includes various types of sedentary behavior (SB) and physical activity (PA) with varying levels of intensity^{4,5}. Sufficient amounts of PA are postulated to be beneficial for health^{6,7}. After a stroke, however, the amount of PA is reduced and remains below recommended levels^{1,8} and is lower in community-walking people with stroke compared to healthy persons and persons with other chronic conditions^{2,6,9,10}. In addition, people with stroke show more SB than age-matched healthy controls¹. SB is defined as any waking behavior characterized by an energy expenditure of ≤ 1.5 metabolic equivalents of task (MET) while in a sitting, lying, or reclining position¹¹. A longitudinal cohort study showed that people with stroke spent 81% of their waking time in a sedentary state, independent of functional ability¹². Evidence also indicates that prolonged periods of SB significantly increase the risk of all-cause mortality and cardiovascular diseases, independent of a sufficient amount of PA^{13,14}.

Accurate measurement tools are mandatory to objectively measure movement behavior and explore the relationship between SB and health in people with stroke. In people with stroke, several accelerometers have already been validated¹⁵⁻²⁰, indicating that these activity monitors are valid in measuring PA in people after stroke, expressed as steps and energy expenditure in people with stroke. However, these devices do not have a specific focus on SB and measuring different movement types and postures.

The commercially available Activ8 accelerometer can differentiate between the different elements of movement behavior (lying, sitting, standing, walking, cycling, and running) and their metabolic equivalents²¹. Based on the specifications of the instrument, the Activ8 could be promising in daily practice and for research purposes in stroke survivors, as it is a user-friendly and low-cost device. The Activ8's hardware is relatively inexpensive, the software is available for free, it is comfortable to wear, and it is able to continuously monitor up to thirty days²². Additionally, the Activ8 can provide real-time feedback on behavior, which seems to be promising when trying to change movement behaviors, such as decreasing SB and increasing PA²³.

In a healthy population, Activ8 data showed a high correlation (90.1%) with results from video analysis²¹. Sensitivity scores ranged from 81% to 98%, although the Activ8 appeared to have difficulties differentiating between lying and sitting in healthy adults. However, the differentiation between lying and sitting is of less interest because the most relevant function of an accelerometer is to differentiate between SB and time spent at different levels and types of PA¹¹. The Activ8 has already been investigated in a stroke population²⁴. However, in

this study, the Activ8 underestimated upright position by 3.8% and overestimated sedentary time by 4.5%²⁴ while being affixed to the less affected leg. The recommended location for wearing the Activ8 is in the pocket of the trousers²². The validity of the data obtained in this position is currently unknown. Testing the validity using a standardized protocol and determining structural validity is needed^{25,26}.

To determine the structural validity in the natural context of the participant, another accelerometer can serve as a reference method if it provides a sensitivity and specificity of at least 90%²⁵. According to other studies, the MoveMonitor was able to serve as a reference criterion method^{27,28} and has been validated in other impaired groups²⁷⁻³¹. Recently, a walking speed of at least 0.93 m/s was defined as a cut-off value to indicate full ambulation in community-walking people with stroke³². Measuring movement behavior in the community is complicated due to individual, environmental, and contextual factors that make it challenging to measure^{32,33}. In addition to non-community-ambulatory people with stroke, community walkers seem to have low levels of physical activity and high amounts of sedentary behavior; therefore, improving their movement behavior is essential for secondary prevention^{2,12}.

Therefore, the aim of this study is to investigate 1) the criterion validity of the Activ8 in community-walking people with stroke regarding movement behavior (sedentary behavior, standing, walking and cycling) using a standardized protocol and video recordings as a reference and 2) the structural validity of the Activ8 in community-walking people with stroke when measuring movement behavior (sedentary behavior, standing, walking and cycling) in daily life with the MoveMonitor as a reference accelerometer. In both situations, the Activ8 was worn in the recommended position (front pocket).

Methods

Design and participants

A cross-sectional study was performed to investigate the criterion validity and structural validity of the Activ8 in people with stroke using the MoveMonitor as a reference standard. A convenience sample of community-walking people with stroke was recruited from the Department of Neurology of University Medical Center Utrecht, the Center for Geriatric Rehabilitation de Parkgraaf Utrecht and primary care practice VitaForum Bakel, all in The Netherlands between February 2016 and June 2017.

Participants were eligible for inclusion when they had a clinically confirmed stroke, were ≥ 18 years of age, were able to independently perform daily activities such as walking, sitting, standing, and lying were community walkers³² and was able to understand and speak Dutch. Participants were excluded if their cognitive abilities were severely affected, based on the opinion of their health care professional, or if they were not able to secure the elastic belt of the MoveMonitor around the waist with or without help in their home setting. Based on consensus recommendations, at least ten participants needed to be included in this validity study²⁵.

All participants provided informed consent before participation. The study was approved by the Medical Ethics Committee of the University Medical Center Utrecht, The Netherlands (15-768/C).

Accelerometers

The Activ8 measures body postures and movements. The Activ8 (trademark of Remedy Distributions Ltd.) is a small (30x32x10 millimeter), lightweight (20 grams) triaxial accelerometer. The Activ8 contains a battery, a real-time clock, and a medium for data storage. The battery has a capacity of sixty days. The Activ8 stores postures and movements (lying, sitting, standing, walking, cycling, and running) and is set to collect data in epochs of five seconds. In each epoch, the Activ8 registers eight activity counts. The recommended location to wear the Activ8 is in the front pocket of the trousers.

To investigate structural validity, the MoveMonitor was used. The MoveMonitor is a small (83x9x51 millimeters) and lightweight (47 grams) triaxial accelerometer (DynaPort MoveMonitor, Mc Roberts)³⁴. Data were stored on a secured digital memory card. It detects six activities: lying, sitting, standing, locomotion, shuffling, and cycling. The MoveMonitor was set to collect data in one-second epochs and positioned at the lower back with an elastic belt.

Procedure

The following participant characteristics were obtained from the medical records: type of stroke (a hemorrhagic stroke or infarction), location of the stroke, time since stroke, age, and sex. All measurements were performed by author S.K., with the aid of two research assistants. Before conducting the standardized protocol, Barthel index scores were obtained to measure the level of independence in daily living³⁵. The investigator scored walking ability with the functional ambulation category (FAC) scale³⁶, registered walking aids, and measured height and weight. Finally, the participants completed the ten-meter walking test three times to determine comfortable walking speed.

Criterion validity: laboratory protocol

The Activ8 was set before starting the measurement protocol, and the internal clock was automatically synchronized with the time on the computer. The participants performed the following movements according to a standardized 22-minute protocol (Table 1): lying, sitting, standing, walking, walking on a treadmill, and cycling. For the Activ8, the detection of lying is based on the absence of signals for a time interval longer than five minutes. Therefore, the 'lying' task was set at a duration of seven minutes. All other tasks were performed for 90 seconds. The participants wore the Activ8 in the front pocket of their trousers on the nonparetic leg side. If the participant was not able to perform a specific activity, this part of the protocol was omitted. Video recordings were made as a reference method.

Table 1. Testing protocol

ACTIVITY	TIME (SECONDS)
WALKING ON A NORMAL SURFACE (SELF-SELECTED WALKING SPEED, TYPICAL OF THEIR NORMAL WALKING SPEED)	90
SITTING ON A CHAIR	90
STANDING WITHOUT SUPPORT	90
TREADMILL WALKING:	
2 KM/H	90
3 KM/H	90
4 KM/H	90
5 KM/H	90
LYING, SUPINE POSITION	420
CYCLING ON A HOME TRAINER 65-70 RPM*	90

* Revolutions per minute

Structural validity: during daily living

To determine structural validity in their natural context, the participants wore both accelerometers (Activ8 and MoveMonitor) simultaneously for two consecutive days during waking hours. Clear wearing instructions were given verbally and on paper. A valid measurement day was defined by 10 hours of continuous data output²⁰. The participants registered wearing time, recorded wearing comfort in a log, and sent the devices back after 48 hours by mail.

Data processing

Criterion validity: laboratory protocol

The data output of the Activ8 was first transformed from counts to seconds per activity using a conversion tool (2M Engineering) and labeled afterward. Categories observed on the video were taken as a criterion measure. Finally, video footage and accelerometer output were synchronized for comparison purposes. For each posture or movement, the middle 60 seconds of a 90-second registration period of recorded activity were used for further statistical analysis. The data output of the Activ8 and video footage were compared second by second. Two independent raters (S.K. + D.J.) labeled each second in one of the following categories in the (video) footage/output: sedentary (sitting or lying), standing, walking, and cycling. All calculations and classifications were independently performed by the two raters. Agreement and nonagreement were labeled per second.

Structural validity: natural context

The data output of the Activ8 and MoveMonitor were compared over 48 hours; nonwear time was excluded based on the observed wearing time. The MoveMonitor data were uploaded to the manufacturer's website for blinded analysis. The algorithm consisted of five components, as described in earlier studies²⁹. The results were returned in Excel files, with a start and end time for each activity in seconds, and compared with the activity counts from the Activ8. The time spent in each category was summed, and percentages were calculated for each category.

Statistical analysis

Statistical analyses were performed in SPSS 22.0 and Microsoft Office Excel 2010. Descriptive analyses were used to describe participant characteristics.

Criterion validity

The agreement and nonagreement between the video footage and Activ8 output were determined for the following categories: sedentary, standing, walking, and cycling. Additionally, lying and sitting were separately analyzed alongside sedentary. Sensitivity, specificity, and positive predictive values (PPVs) were calculated and presented with

standard deviations for each category. In table 2, explanations of the calculations are given. Scores below 0.60 demonstrate poor sensitivity; between 0.60 and 0.75, moderate sensitivity; and between 0.75 and 1.00, good sensitivity³⁷.

Structural validity

The structural validity of the Activ8 was determined by defining the agreement between the Activ8 and MoveMonitor for sedentary, standing, walking, and cycling using the percentages of their distributions over 48 hours.

Intraclass correlation coefficient (ICC 3,1) analysis was conducted using a two-way model in which random effects were assumed for the participants and fixed effects for the accelerometer³⁸. The Bland-Altman method³⁹ was used to test agreement of data output between the MoveMonitor and the Activ8 for the categories sedentary, standing, walking, and cycling. Mean differences and limits of agreement (LOA) (within mean \pm 1.96 standard deviations of the mean difference) were obtained and presented. The MoveMonitor output was used as the reference standard. ICC values \geq 0.80 indicate excellent structural validity; between 0.60 and 0.80, sufficient; between 0.40 to 0.60, moderate; and below 0.4, poor⁴⁰.

Table 2. Example calculations for sensitivity, specificity, and positive predictive values.

ANALYSIS	METHOD
SENSITIVITY	(the total duration that the video and the Activ8 agreed at the same second for walking/total duration that walking was observed on video) x 100%
SPECIFICITY	(the total duration that the video and the Activ8 agreed at the same second for not walking/total duration that not walking was observed on video) x 100%
POSITIVE PREDICTIVE VALUE	(the total duration that the video and the Activ8 agreed at the same second for walking/ total duration that walking was reported by the Activ8) x 100%

Results

In total, eleven participants were included. The mean comfortable gait speed was 1.49 \pm 0.34 m/s. Two of the participants did not score the maximum number of points on the Barthel index. The wearing comfort of the Activ8 was reported in 91% of the cases as comfortable. Table 3 presents the participants' characteristics.

Table 3. Participant characteristics

SEX (MALE:FEMALE)	9:2
AGE (YEARS) (MEAN\pmSD)	62.6 \pm 12.3
LENGTH (CM) (MEAN\pmSD)	174 \pm 9.7
WEIGHT (KG) (MEAN\pmSD)	85 \pm 18
TYPE OF STROKE	11
INFARCTION	10
HEMISPHERE	2/8
LEFT/RIGHT	1
CEREBELLUM	
TIME SINCE STROKE (MONTHS) (MEAN\pmSD)	18.5 \pm 10.7
COMFORTABLE GAIT SPEED (M/S) (MEAN\pmSD)	1.49 \pm 0.34
BARTHEL INDEX (0-20)	20 (18-20)
(MEDIAN (RANGE))	
FAC SCORE (MEDIAN (RANGE))	5 (4-5)
WALKING AID	walker (n=2)

SD= standard deviation, cm=centimeter, kg=kilogram, m/s= meter per second, FAC=functional ambulation categories

Criterion validity

Data from 11 participants were used for the analyses of sedentary behavior, standing, and walking. Out of 11 participants, one participant was not able to cycle on a home trainer.

Table 4 presents the sensitivity, specificity, and PPV scores of the Activ8 results for all participants. All sensitivity scores were good, with a range from 76.3% to 91.9. Further details about the specificity and PPVs are presented in table 4.

Table 4. Sensitivity, specificity, positive predictive values of the Activ8. Values are presented as percentages (mean \pm SD) (n=11)

ACTIVITY	SENSITIVITY	SPECIFICITY	POSITIVE PREDICTIVE VALUE
SEDENTARY	91.9 \pm 5.1	97.9 \pm 2.7	97.0 \pm 3.9
STANDING	81.9 \pm 12.6	98.6 \pm 1.3	93.9 \pm 6.0
WALKING	80.8 \pm 27.6	92.4 \pm 5.7	69.7 \pm 26.5
CYCLING (N=10)	76.3 \pm 22.8	97.5 \pm 7.9	100.0 \pm 0

Structural validity

The ICCs between the Activ8 and MoveMonitor were excellent for standing, walking, and cycling, ranging between 0.88 and 0.91. The ICC for sedentary time was sufficient at 0.76. All ICC scores are presented in table 5. The mean difference and 95% LOA showed that the Activ8 measured less sedentary and cycling time compared to the MoveMonitor. In contrast, the Activ8 marginally overestimated standing and walking compared to MoveMonitor.

Table 5. Structural validity of the Activ8 compared to the MoveMonitor (n=11)

ACTIVITY	ICC (95% CI)	MEAN DIFFERENCE IN PERCENTAGES BETWEEN THE ACTIV8 AND MOVEMONITOR (95% LIMITS OF AGREEMENT)
SEDENTARY	0.76 (0.17 to 0.94)	-6.02 (-12.33 to 0.30)
STANDING	0.91 (0.68 to 0.98)	1.32 (-2.73 to 5.37)
WALKING	0.88 (0.42 to 0.97)	2.01 (0.25 to 3.76)
CYCLING	0.90 (0.64 to 0.97)	-0.21 (-0.95 to 0.51)

ICC= intraclass correlation coefficient CI=confidence interval

Discussion

This study aimed to determine the criterion and structural validity of the Activ8 accelerometer for measuring sedentary behavior, standing, walking and cycling in people with stroke using a standardized protocol and in the natural context of the participant, using the recommended position of the Activ8 in the front pocket of the trousers. The results of this study indicated that the Activ8, worn in the pocket of the trousers, has good criterion validity for SB and PA (standing, walking, and cycling) in community walkers with stroke. Additionally, the Activ8 showed substantial to excellent structural validity.

In general, our results are comparable to the study of Fanchamps et al.²⁴. This study investigated the agreement of the Activ8 versus video footage in people with stroke during protocolled activities and daily life activities during a maximum assessment time of one hour²⁴. The results for the validity of the Activ8 for the different activities were slightly better compared to the present study, which probably can be explained by the wear position of the Activ8. In a previous study with healthy subjects, the results of the validity of the Activ8 were higher when the device was fixed to the thigh compared to the wear position in the front pocket. Although a fixed wearing location results in more sensitive scores, research has shown that wearing comfort is essential for adherence^{41,42} when wearing the device over a long period of time. In our study, wearing comfort of the Activ8 was positively reviewed in 10 out of 11 participants.

People with stroke tend to walk slower and have different movement patterns compared to people without stroke¹⁵. The accuracy of accelerometers is prone to decrease when gait speed and step frequency decrease^{16,43,44}. Therefore, we included walking on a treadmill at different walking speeds in the laboratory protocol to detect the influence of walking speed on the accuracy of the Activ8. In the present study, analysis of agreement between treadmill walking and video observations showed an agreement of 80%. Therefore, different walking speeds were measured accurately with the Activ8. However, gait patterns on a treadmill are more symmetrical and challenging to compare to daily life walking, which shows more variation in gait speed⁴⁵. In the study of Fanchamps et al., the variation in gait speed was higher, and the overall gait speed was lower, yet validity was found to be good²⁴. To ensure that the Activ8 is accurately detecting walking, research in non-community-walking people with a stroke is needed.

Structural validity between the Activ8 and MoveMonitor output was excellent in the categories standing and walking and sufficient in the category SB. To our knowledge, this is the first study in people with stroke testing the structural validity of body postures and movement measured with two accelerometers in daily life over the course of 48 hours.

Other accelerometers have been, in contrast with the method used in our study, compared with diary logs or activity energy expenditure with doubly labeled water^{30,38,46,47}. In the absence of a gold standard, a comparison with an existing accelerometer that measures the same structure is appropriate³⁴. Although recent validation studies have confirmed that the MoveMonitor can correctly detect postures and movement in participants with impairments²⁷⁻³¹, using the MoveMonitor as a reference method in daily life could have resulted in some limitations in the present study. Two studies reported that the MoveMonitor has difficulties differentiating between standing and sitting (82% incorrect detection)^{27,28}. However, two other studies showed excellent agreement for standing (88-97%) and sitting (91-99%)^{48,49}. In our study, the LOA were small, suggesting that the Activ8 and MoveMonitor assessed movement behavior in a reasonably similar manner.

A strength of this study is the validation of the Activ8 both in a laboratory setting and in daily life. This approach provided the ability to precisely compare the Activ8 output with the reference standard for each posture and movement²⁵. Furthermore, the daily living component of this study provided insight during spontaneous activity in real life and therefore represents ecological validity^{25,26,50}.

Although the results of this study provide essential information regarding the use of the Activ8, some limitations should be mentioned. The measurement time per activity in the laboratory protocol was rather long, while in real life, activities consist of shorter bouts. Activities with shorter time periods are supposed to be harder to detect with an accelerometer⁴⁶ since an accelerometer often needs adjustment time between two different activities correctly. Our measurement protocol was adjusted to allow for transfer time between two different activities. However, the agreement between the Activ8 and video footage in daily activities in the study of Fanchamps et al. showed a comparable level of agreement²⁴.

The Activ8 is accurate in differentiating between SB and different activities (standing, walking, cycling). The definition of SB includes 'any waking activity in a sitting or reclining posture characterized by an energy expenditure of ≤ 1.5 metabolic equivalents^{8,12}. Therefore, it was not interesting to differentiate between lying and sitting in the analysis for this study. However, when separately evaluating lying and sitting, the results showed difficulties in the discrimination of lying. This should be kept in consideration when the Activ8 is used in clinical research or practice. Clearly identifying the purpose of the use of an accelerometer is of importance for both practice and research²⁴.

The Activ8 is able to differentiate between body postures and activities in a valid way. Such a device is needed to provide people with stroke insight into their movement behavior.

Additionally, the Activ8 can provide important information to health care professionals. Based on the information, the health care professional is able to coach and provide adequate feedback on the behavior. Important behavior change techniques can be implemented to improve movement behavior²³. The Activ8 could be a useful instrument in intervention strategies to improve the movement behavior of people with stroke.

Conclusion

The present study showed that the Activ8 is a valid tool to measure movement behavior and the included SB, standing, walking, and cycling postures in community-walking people with stroke, both in the laboratory setting and in daily life. Therefore, the Activ8 seems to be a promising monitoring tool for coaching strategies directed at behavioral movement change in people with stroke.

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CHAPTER 5



MOVEMENT BEHAVIOR REMAINS STABLE IN STROKE SURVIVORS WITHIN THE FIRST TWO MONTHS AFTER RETURNING HOME

Roderick Wondergem

Martijn F. Pisters

Martijn W. Heymans

Eveline J.M. Wouters

Rob. A. de Bie

Cindy Veenhof

Johanna M.A. Visser-Meily

Abstract

Background and purpose

The aim of this study is to investigate changes in movement behaviors, sedentary behavior, and physical activity, and to identify potential movement behavior trajectory subgroups within the first two months after discharge from the hospital to the home setting in first-time stroke patients.

Methods

A total of 140 participants were included. Within three weeks after discharge, participants received an accelerometer, which they wore continuously for five weeks to objectively measure movement behavior outcomes. The movement behavior outcomes of interest were the mean time spent in sedentary behavior (SB), light physical activity (LPA), and moderate to vigorous physical activity (MVPA); the mean time spent in MVPA bouts ≥ 10 minutes; and the weighted median sedentary bout. Generalized estimation equation analyses were performed to investigate overall changes in movement behavior outcomes. Latent class growth analyses were performed to identify patient subgroups of movement behavior outcome trajectories.

Results

In the first week, the participants spent an average of 9.22 hours (67.03%) per day in SB, 3.87 hours (27.95%) per day in LPA, and 0.70 hours (5.02%) per day in MVPA. Within the entire sample, a small but significant decrease in SB and an increase in LPA were found in the first weeks in the home setting. For each movement behavior outcome variable, two or three distinctive subgroup trajectories were found. Although subgroup trajectories for each movement behavior outcome were identified, no relevant changes over time were found.

Conclusion

Overall, the majority of stroke survivors are highly sedentary, and a substantial part is inactive in the period immediately after discharge from hospital care. Movement behavior outcomes remain fairly stable during this period, although distinctive subgroup trajectories were found for each movement behavior outcome. Future research should investigate whether movement behavior outcomes cluster in patterns.

Introduction

The majority of stroke survivors are discharged to the home setting immediately after hospital care¹. Following a stroke, cardiovascular event rates are high. Premature death and disability rates are higher after a recurrent event than after the first stroke^{2,3}. Secondary lifestyle interventions are important and have been demonstrated to be effective in reducing systolic blood pressure, one of the strongest risk factors for both first and recurrent stroke^{4,5}. An important lifestyle intervention that can favorably influence cardiovascular risk is changing movement behaviors⁶. Movement behaviors during waking hours include sedentary behavior (SB), and physical activity (PA)⁷. Within PA, the intensities of light physical activity (LPA) and moderate to vigorous physical activity (MVPA) can be distinguished. SB is defined as “any waking activity characterized by an energy expenditure of ≤ 1.5 metabolic equivalents (METs) and a sitting or reclining posture”⁸, LPA consists of activities between 1.5 and 3.0 METs, and MVPA consists of all activities > 3.0 METs. In general, stroke survivors are highly sedentary and inactive compared to healthy peers⁹.

Various movement behavior outcomes have shown associations with health risk and functional decline^{10,11}. The composition of movement behavior during waking hours (the relative amounts of SB, LPA, and MVPA during waking hours), the continuity of SB (interrupted or prolonged SB), and the continuity of MVPA (bouts ≥ 10 minutes) are important modifiable risk factors to improve cardiovascular health. High amounts of SB and low amounts of MVPA are independent risk factors for cardiovascular disease incidence and premature mortality. MVPA should occur in bouts of at least ten minutes to contribute to the recommended 150 minutes per week spent in MVPA¹². Additionally, long uninterrupted sedentary bouts are related to cardiovascular risks¹³. Interrupting SB after 20 minutes has been found to have a positive influence on glucose levels in overweight people¹⁴, and interruption after 30 minutes decreased the systolic blood pressure of stroke survivors¹⁵, thus providing cardiovascular health benefits.

Few longitudinal studies have investigated changes in movement behavior during waking hours in stroke survivors. Two small longitudinal studies focusing on the first three months after discharge from a rehabilitation hospital stroke unit found significant increases in both LPA and MVPA¹⁶. In contrast, another study found an increase in SB¹⁷. To date, all studies investigating the course of movement behavior outcomes up to the first year after stroke have used averaged group data and found no changes over time^{9,16,18,19}. However, recovery after stroke is not a one-size-fits-all principle; it is characterized by individual patterns²⁰. Previous studies have demonstrated variation in the trajectories of physical and psychosocial health-related quality of life²¹ and functional recovery²² within the first year after stroke. In healthy populations, SB and MVPA were found to have four to seven subgroup trajectories each^{23,24}.

Because the stroke recovery process is heterogeneous, different subgroup trajectories of movement behavior outcomes can be expected.

The hypothesis is that a decrease in total sedentary time, increased interruption of SB, and increases in LPA and MVPA will occur in the initial period after discharge. These outcomes might be expected because most functional recovery occurs within the first few weeks after stroke²⁰, and most stroke survivors still receive professional support or rehabilitation during that period²⁵. Moreover, during those initial weeks, health care professionals provide information regarding modifiable risk factors, including movement behaviors²⁶. Additionally, it is expected during the period shortly after this life event, are especially motivated to improve their lifestyle to prevent recurrent events²⁷. Therefore, the trajectories of changes in movement behavior outcomes are expected. However, knowledge is currently lacking regarding the course of movement behavior outcomes shortly period after discharge.

Stroke recovery is heterogeneous, and average group data, assumes a one-size-fits-all principle, possible changes in movement behavior outcomes in subgroup trajectories may be overlooked. Therefore, subgroup trajectories of change in movement behavior outcomes need to be investigated, since they are expected. To identify potential subgroup trajectories, data-driven analyses are needed. Latent class growth analysis is a method whereby participants are assumed to belong to a single class but which class is not known²⁸. This approach will extend our understanding of subgroup trajectories of change in movement behavior outcomes. Once these subgroup trajectories are known, associations will need to be explored. Currently, only a few associations are known with regard to movement behavior outcomes. Lower walking speed and walking capacity, balance problems, presence of depression and poorer quality of life associated with accelerometer activity counts⁹. Additionally, higher age, being a man, higher cardiorespiratory fitness, lower levels of fatigue, a higher level of self-efficacy, presence of depression, and higher health-related quality of life were factors associated with higher levels of PA²⁹. Lower walking speed was found to associated with a higher amount of sedentary time and long prolonged bouts³⁰, less functional independence with high amounts of sedentary behavior and prolonged bouts, stroke severity with high amounts of sedentary behavior and age with more prolonged sedentary behavior¹⁹. Although these studies provide preliminary information, a deeper understanding of factors related to single movement behavior outcomes is needed.

Therefore, the aim of the current study is 1) to investigate changes in both the distribution (SB, LPA, and MVPA) and accumulation (bouts) of movement behavior during waking hours for the entire sample, and 2) to detect possible subgroup trajectories within each movement behavior outcome within the first two months after discharge from hospital care to the home setting in first-time stroke patients. Once these subgroup trajectories are known, 3) associated patient characteristics will be explored.

Methods

Design and participants

Eligible participants were recruited between February 2015 and April 2017 from four participating stroke units in the Netherlands. This prospective longitudinal cohort study carried out after discharge from a hospital directly to the patients' own home settings, specifically recruited persons who had suffered a clinically confirmed first-ever stroke and who had been independent in ADL before stroke (Barthel index score >18 ³¹). Other inclusion criteria were age over eighteen years, ability to sustain a conversation (Utrecht Communication Assessment score >4 ³²), and at least the ability to walk with supervision after stroke (Functional Ambulation Categories score >2 ³³). People with subarachnoid hemorrhage were excluded. The written informed consent of the participants was obtained at the stroke unit. The study was approved by the Medical Ethics Research Committee of the University Medical Center Utrecht (study number 14/76).

Measurements and procedures

After discharge from the hospital, participants were visited at home within three weeks after discharge. During this visit, walking speed, balance, and levels of activity and participation were obtained. Participants received an accelerometer to objectively measure movement behavior during waking hours. The participants wore the accelerometer for five consecutive weeks before returning the device by mail.

Independent characteristics

The personal characteristics obtained were the age and sex of the participants and whether they lived alone. Stroke severity was measured with the National Institute of Health Stroke Scale (NIHSS) (range 0-42, with higher scores indicating more severe stroke symptoms). The NIHSS discerns three subgroups: 1) no stroke symptoms (0 points); 2) minor stroke (1-4 points); and 3) moderate to severe stroke (≥ 5 points)³⁴. Stroke services are a form of integrated care that has been established during the last decade. The aim of stroke services is to improve health outcomes and processes of care by connecting the acute, rehabilitative, and chronic phases of stroke care^{35,36}. In a typical Dutch stroke service, the hospital, rehabilitation center (in- or outpatient care), and primary physiotherapy care are represented. Information about physiotherapy care was obtained from medical records and verified by asking the participant. Three options were possible: no physiotherapy care, primary physiotherapy care, and outpatient multidisciplinary rehabilitation care that included physiotherapy. The Montreal Cognitive Assessment was used to assess cognitive functioning^{37,38}. Scores were dichotomized into normal (≥ 26) or impaired (< 26) cognitive function. The Hospital Anxiety and Depression Scale was used to assess the presence of depression and anxiety symptoms. Each subscore was dichotomized into the presence (≥ 8 points) or absence (< 8 points) of depression or anxiety

symptoms^{39,40}. The Late-Life Function and Disability Instrument Computerized Adaptive Test activity limitations and participation restriction subscales scores were obtained⁴¹. Physical functioning was measured with the physical functioning subdomain of the Stroke Impact Scale (SIS) 3.0^{42,43}. The physical functioning subdomain consists of ten questions regarding ADL, eight regarding mobility, and five regarding hand function^{42,43}. As recommended, scores were calculated as percentages of the total points, resulting in a range from 0 to 100. Lower scores indicate lower levels of physical functioning. The balance was tested with the Berg Balance Scale⁴⁴. Walking speed was obtained using the five-meter walk test⁴⁵. All outcome measures are valid and reliable in a stroke population.

Accelerometer

Movement behavior during waking hours was objectively measured with an Activ8 accelerometer. The Activ8 is a triaxial accelerometer (30x32x10 mm, 20 grams). Participants were instructed to carry the accelerometer in the front pocket of their pants on the unaffected leg the whole day during waking hours. Only when taking a shower or swimming were participants allowed to remove the device. Clear wearing instructions were given, and participants were asked to record in an activity log the time when they put on the Activ8 in the morning and the time when they removed it. The device can detect SB (a combination of reclining and sitting), standing, walking, cycling, and running and provide corresponding MET values. The Activ8 measures with a sampling frequency of 12.5 Hz, an epoch of 1 second, and a sample interval of 5 seconds. Every 5 minutes, a summary was stored of the different postures and their respective MET values. The device is able to store data for sixty days, and its battery life is at least 30 days⁴⁶. The Activ8 has been validated in a community-living stroke population in terms of postures and in a healthy population in terms of energy expenditures^{47,48}.

Movement behavior outcomes

Individual days were screened, and nonwear time was removed from the data files using starting and stopping times. Using SPSS, the most important and recommended movement behavior outcomes were calculated⁴⁹. The mean times spent in SB, LPA, and MVPA in hours per day were computed by summation and divided by the number of wearing days per individual⁷. The mean time of MVPA accumulated in bouts ≥ 10 minutes was calculated. An MVPA bout was defined as 10 or more consecutive minutes of MVPA, with allowance for interruptions of no more than 2 minutes⁵⁰. For each individual, the weighted median sedentary bout length was calculated⁴⁹. The weighted median sedentary bout is the sedentary bout that corresponds to 50% of the total sedentary time⁴⁹. The weighted median sedentary bout length is more sensitive to change than the total time spent in SB⁵¹. Bouts are ordered from smallest to largest, and for example, if an individual has spent eight hours sedentary, this measure represents the length of the bout that contains the four hour timepoint. If this would be 20 minutes, it means that individuals spend 50% their SB time in bouts ≥ 20 minutes. The lower the weighted median sedentary bout is, the more frequently interrupted the SB.

Data analysis

SPSS version 25.0⁵² was used for descriptive statistics, which are expressed as the means and standard deviations. The multivariate imputation by chained equation procedure was used to impute (multiple) missing values⁵³. In our data set, missing data were not dependent on descriptive characteristics; therefore, data were assumed to be missing completely at random, and multivariate imputation by chained equations was therefore indicated to increase statistical power⁵⁴. Multivariate imputation by chained equations was performed by models to predict missing values for a given variable based on all other observed variables. Five imputed data sets were created and combined to create a pooled set using Rubin's rules⁵⁵.

To investigate the average group movement behavior change within the first weeks after discharge to the home setting, generalized estimation equation were employed⁵⁶. Latent class growth analysis was performed with Mplus version 8.1⁵⁷ to identify clinically relevant homogeneous subgroups of stroke survivors that followed different trajectories of movement behavior. For each movement behavior outcome, latent class growth analysis was performed. Latent class growth analysis uses latent variables to estimate differences in mean changes over time in different subgroups, taking into account individual longitudinal trajectories. The trajectories within the subgroups were kept homogenous. The fit of the models was tested by comparing models with two, three, four, and five subgroups. Both linear and quadric trajectories were modeled and compared. Statistical considerations for finding the most appropriate model included a Bayesian information criterion, entropy values, and the bootstrap likelihood ratio test⁵⁸⁻⁶⁰. The lower the Bayesian information criterion score, the better the fit of the model⁶⁰. When bootstrap likelihood ratio test was significant ($p < 0.05$), the model with k -subgroups had a better fit than the model with $k-1$ trajectory subgroups^{28,60}. The entropy statistic was used for the reliability of the subgroup trajectories. Entropy scores above 0.8 are preferred²⁸. When less than 5% of the sample was assigned to a subgroup trajectory, a $k-1$ subgroup trajectory model was chosen⁶¹.

If more than two subgroup trajectories were found based on the latent class growth analysis, trajectories were merged into two clinically relevant subgroups. To determine the characteristics associated with a single subgroup trajectory, logistic regression analyses were performed. Odds ratios were calculated to identify candidate factors using univariate analyses. The related variables were tested for multicollinearity (Pearson's $r < 0.70$) and effect modification (variance inflation factor > 4)⁶². Significantly associated characteristics ($p < 0.1$) were entered into a multiple backward logistic regression analysis.

Results

In total, 180 people with stroke agreed on participation when discharged from the hospital to the home setting. With twenty persons, it was not possible to make an appointment

within three weeks, fifteen refused further participation, three were unable to contact, one was too ill, and one died before our visit. Resulting in 140 participants included in this study. The mean age of the population was 66.4 years, and the majority of the population was male (66.4%). Stroke severity two days after stroke was mild in 63.6% of the population. Other characteristics are presented in table 1.

In total, 4.81% of the movement behavior outcomes were missing and imputed. The mean Activ8 wear time in week one was 13.78 hours per day and did not change during the subsequent four assessment weeks. The overall mean sedentary time during the five consecutive weeks was high, with a mean of 9.22 hours in week one, with a significant average decrease of 0.06 hours per week, leading to 8.9 hours in week five. The time spent in LPA was 3.87 in week one, increasing significantly by 0.05 hours per week, leading to 4.08 hours. All other movement behavior outcomes remained stable over time. The mean time spent in MVPA was 0.70 hours in week one, and MVPA accumulated in bouts ≥ 10 minutes in week one was 0.29 hours. A mean weighted median sedentary bout of 21.82 minutes was found in week one. All movement behavior outcomes by week and all generalized estimating equations outcomes can be found in table 2.

Different amount of subgroup trajectories were found for movement behavior outcomes (see table 1, supplementary materials, for the Bayesian information criterion, entropy, and bootstrap likelihood ratio test outcomes for each subgroup trajectory). Although the fit of most models favored a four or five subgroup model, some subgroup trajectories contained too few individuals to be considered clinically relevant (less than 5% of the total sample). Consequently, two subgroup trajectories were determined for SB and LPA. Three subgroups were found for MVPA, MPVA spent in bouts ≥ 10 minutes, and weighted median sedentary bouts. For total SB, LPA, and MVPA, quadratic trajectories are presented because lower Bayesian information criterion values and higher entropy values were found. Linear trajectories were presented for weighted median sedentary bouts, and MVPA accumulated in bouts ≥ 10 minutes. The Bayesian information criterion, entropy, bootstrap likelihood ratio test, intercepts, and slopes are presented in table 3. All presented subgroup trajectories had entropy scores above 0.8.

Table 1. Participant characteristics expressed as mean±SD, median [IQR], or n (%)

Characteristics (N=140)	% or mean±SD
Personal characteristics	
Males	66.4
Age (years)	67.1±10.8
Living alone	18.6
Stroke characteristics	
Time since stroke (days)	19.6±5.6
Infarction	91.4
Side of stroke	
Left	52.9
Right	42.1
Both	2.1
Unknown	2.9
Stroke severity day 2 after stroke	
No symptoms (NIHSS 0)	15.0
Minor stroke symptoms (NIHSS 1 to 4)	63.6
Moderate to severe stroke symptoms (NIHSS ≥5)	21.4
Psychological characteristics	
Cognitive functioning ^a	
Impaired cognitive function (MOCA ≤25) ^a	39.1
Depression (HADS-D)	13.7
Anxiety (HADS-A)	16.7
Physiotherapy care	
Outpatient multidisciplinary rehabilitation, including physiotherapy ^a	12.8
Primary care physiotherapy ^a	33.6
No physiotherapy ^a	53.6
Functional ability	
Walking speed (m/s) ^a	1.03±0.24
Limited community walker (≤0.93 m/s) ^a	31.4
LLFDI-CAT activity limitations ^a	58.9±10.8
Physical functioning (SIS)	93.8 [82.3-98.9][48.9±10.7
LLFDI-CAT participation restrictions ^a	55 [52.2-56]
Balance (BBS)	

%= percentage, SD= standard deviation, IQR= interquartile range, NIHSS = National Institutes of Health Stroke Scale, MOCA= Montreal Cognitive Assessment, HADS= Hospital Anxiety and Depression Scale, m/s= meters per second, LLFDI-CAT= Late-Life Function and Disability Instrument Computer Adaptive Testing, SIS= Stroke Impact Scale, BBS= Berg Balance Scale

^a Assessments were carried out in the participant's home setting within three weeks after discharge from inpatient care (hospital or inpatient rehabilitation).

Higher scores indicate better outcomes except for walking speed.

The stroke survivors allocated to the two subgroup SB trajectories spent a mean of 7.92 and 9.94 hours in SB, respectively. In this manner, 64.3% were classified as 'highly sedentary' and 35.7% as 'less sedentary'. The time spent in LPA varied between 3.17 and 5.02 hours. A

total of 65.7% of the participants were classified as 'nonmovers', and 34.3% were classified as 'movers'. Three subgroups were found regarding MVPA and MVPA spent in bouts ≥ 10 minutes. Only 10.7% were identified as 'highly active', while 34.3% were 'active', and 55% were 'inactive'. The results for the time spent in MVPA bouts ≥ 10 minutes were slightly worse. Altogether, 10% of the participants could be classified as 'prolongers', 52.8% as 'intermediate', and 37.1 as 'interrupters', with weighted median sedentary bout lengths of 50 minutes, 24 minutes, and 11 minutes, respectively. All outcomes can be found in table 3.

Figure 1a-e are showing subgroup trajectories of all movement behavior outcomes. A small but significant decrease in sedentary time was found in the subgroup trajectory of highly sedentary people. The inactive subgroup increased slightly in time spent in MVPA, whereas the active subgroup slightly decreased. All other subgroup trajectories of movement behavior outcomes remained stable within the first two months.

The 'active' and 'highly active' subgroup trajectories for both MVPA and MVPA spent in bouts ≥ 10 minutes were merged together since the participants in both subgroups were sufficiently active since international guidelines recommend at least 150 minutes per week of accumulated moderate to vigorous physical activity (MVPA)¹². Additionally, 'intermediate' and 'interrupters' subgroup trajectories for the weighted median sedentary bout length were merged. Although there are no clear cut-off values available for the interruption of SB, interruption after thirty minutes has been found to have health benefits in people with stroke^{63,64}. The distribution of individuals to the different subgroups is presented in supplementary materials table 2. The results show that different movement behavior outcomes reveal distinct trajectories. For example, 53.6% of the population was highly sedentary and classified as nonmovers, and 35.7% was inactive and highly sedentary.

The results of the univariate analyses per movement behavior subgroup are presented in table 4. The results of the multiple logistic regression analyses are presented in table 5. No associations were found regarding SB. Factors associated with nonmovers were living with another person and impaired cognitive function. Being male, and younger and having fewer activity limitations were associated with both active groups (MVPA and MVPA spent in bouts ≥ 10 minutes). Living alone and being a community walker were only associated with the active MVPA group. Factors associated with prolongers were more severe stroke symptoms, cognitive impairment, and not being a community walker.

Table 2. Movement behavior outcomes in the overall group and generalized estimating equations analyses adjusted for wear time

Movement behavior outcome	Week 1 [95%CI]	Week 2 [95%CI]	Week 3 [95%CI]	Week 4 [95%CI]	Week 5 [95%CI]	B [95%]
Sedentary (hours/day)	9.22 [8.94-9.46]	9.18 [8.87-9.49]	9.25 [8.96-9.54]	9.00 [8.71-9.30]	8.99 [8.73-9.26]	-0.06 [-0.11- -0.02]*
LPA (hours/day)	3.87 [3.60-4.13]	3.98 [3.71-4.25]	3.93 [3.68-4.18]	4.06 [3.79-4.33]	4.08 [3.83-4.33]	0.05 [0.01-0.09]*
MVPA (hours/day)	0.70 [0.61-0.78]	0.69 [0.60-0.78]	0.71 [0.62-0.80]	0.65 [0.57-0.74]	0.73 [0.65-0.82]	0.01 [-0.02-0.02]
MVPA accumulated in bouts \geq 10 minutes (hours/day)	0.29 [0.22-0.35]	0.25 [0.20-0.30]	0.25 [0.20-0.30]	0.27 [0.22-0.32]	0.28 [0.23-0.33]	0.00 [-0.01-0.01]
Weighted median sedentary bout (minutes)	21.82 [19.71-23.93]	20.71 [18.49-22.92]	21.85 [19.64-24.06]	21.53 [19.46-23.60]	21.16 [19.17-23.16]	-0.05 [-0.44-0.34]
Wear time (hours/day)	13.78 [13.70-13.87]	13.85 [13.76-13.94]	13.89 [13.79-13.99]	13.81 [13.72-13.91]	13.82 [13.72-13.92]	n.a.

CI= confidence interval, LPA= light physical activity, MVPA =moderate to vigorous physical activity

*P<0.05

Table 3. Model fit indices for the selected subgroup trajectories for each movement behavior outcome, n=140

	Subgroups (n)	Intercept for subgroup	Linear slope	Quadric slope	BIC	Entropy	BLRT																																																																
Sedentary behavior (hours/day)	Highly sedentary = 90	9.94	0.25	-0.06*	2343.72	0.87	<0.01																																																																
	Less sedentary = 50	7.92	-0.37	0.07				LPA (hours/day)	Non-movers = 92	3.17	-0.10	0.03	2192.88	0.82	<0.01	Movers = 48	5.02	0.33	-0.06	MVPA (hours/day)	Inactive = 77	0.43	-0.08*	0.01*	2192.88	0.82	<0.01	Active = 48	1.02	-0.08	0.01	Highly active = 15	1.43	0.21	-0.04*	MVPA bouts ≥ 10 min (hours/day)	Inactive = 89	0.10	0.01	n.a.	-83.89	0.93	<0.01	Active = 42	0.40	0.01	n.a.	Weighted median sedentary bout length (min)	Highly active = 9	1.05	-0.01	n.a.	5151.92	0.91	<0.01	Prolongers = 14	49.97	-1.64	n.a.		Intermediate = 74	23.90	0.17	n.a.					Interrupters = 52	11.00	0.08
LPA (hours/day)	Non-movers = 92	3.17	-0.10	0.03	2192.88	0.82	<0.01																																																																
	Movers = 48	5.02	0.33	-0.06				MVPA (hours/day)	Inactive = 77	0.43	-0.08*	0.01*	2192.88	0.82	<0.01	Active = 48	1.02	-0.08	0.01		Highly active = 15	1.43	0.21	-0.04*				MVPA bouts ≥ 10 min (hours/day)	Inactive = 89	0.10	0.01	n.a.	-83.89	0.93	<0.01	Active = 42	0.40	0.01	n.a.	Weighted median sedentary bout length (min)	Highly active = 9	1.05	-0.01	n.a.	5151.92	0.91	<0.01	Prolongers = 14	49.97	-1.64	n.a.		Intermediate = 74	23.90	0.17	n.a.					Interrupters = 52	11.00	0.08	n.a.							
MVPA (hours/day)	Inactive = 77	0.43	-0.08*	0.01*	2192.88	0.82	<0.01																																																																
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	Interrupters = 52	11.00	0.08	n.a.																																																																			

BIC= Bayesian information criteria, BLRT= bootstrap likelihood ratio test, LPA= light physical activity, MVPA= moderate to vigorous physical activity, min= minutes

*p<0.05

Table 4. Associated factors with highly sedentary, non-movers, active and prolongers using univariate analyses

INDEPENDENT VARIABLES	HIGHLY SEDENTARY			NON-MOVERS (LPA)			ACTIVE (MVPA)			ACTIVE (MVPA BOUTS> 10 MIN)			PROLONGERS (WMSB)		
	OR	95%CI	P	OR	95%CI	P	OR	95%CI	P	OR	95%CI	P	OR	95%CI	P
PERSONAL CHARACTERISTICS															
MALE	1.29	0.61-2.71	0.51	1.30	0.63-2.71	0.48	2.63	1.25-5.54	0.01	5.13	2.09-12.62	>0.01	0.90	0.28-2.86	0.86
LOWER AGE (YEARS)	1.00	0.97-1.04	0.88	1.02	0.98-1.05	0.37	1.06	1.02-1.10	<0.01	1.04	1.01-1.08	0.02	0.95	0.90-1.01	0.08
LIVING TOGETHER	1.71	0.73-4.07	0.22	0.44	0.19-1.05	0.07	2.28	0.95-5.46	0.06	0.91	0.37-2.22	0.83	0.71	0.15-3.38	0.71
STROKE / CARE CHARACTERISTICS															
MORE SEVERE STROKE SYMPTOMS (NIHSS)	1.12	1.00-1.25	0.06	0.90	0.81-1.01	0.08	1.02	0.93-1.12	0.70	1.02	0.93-1.11	0.74	0.90	0.81-0.99	0.04
INFARCTION	1.12	0.32-3.03	0.86	0.96	0.27-3.35	0.94	1.71	0.49-5.97	0.40	1.16	0.33-4.06	0.82	0.52	0.10-2.64	0.43
NO PT CARE	1.37	0.68-2.74	0.38	0.95	0.47-1.92	0.89	0.53	0.27-1.05	0.07	0.69	0.34-1.39	0.30	1.25	0.41-3.77	0.69
PSYCHOLOGICAL AND COGNITIVE FACTORS															
COGNITIVE IMPAIRED (MOCA ≤25)	0.83	0.41-1.67	0.60	2.09	1.01-4.33	0.04	0.97	0.49-1.89	0.92	1.38	0.69-2.77	0.37	4.68	1.23-17.84	0.02
ABSENCE DEPRESSION (<8 HADS-D)	1.68	0.57-4.98	0.35	0.46	0.14-1.48	0.19	1.96	0.70-5.50	0.20	1.30	0.46-3.66	0.62	0.16	0.05-0.52	<0.01
ABSENCE ANXIETY (<8 HADS-A)	0.56	0.23-1.38	0.21	1.00	0.39-2.56	1.00	1.07	0.44-2.65	0.88	1.08	0.42-2.76	0.87	0.64	0.16-2.51	0.52
PHYSICAL FUNCTIONING															
LIMITED COMMUNITY WALKER (≤0.93 M/S)	1.04	0.50-2.19	0.91	1.18	0.55-2.51	0.68	0.11	0.04-0.28	<0.01	0.14	0.04-0.38	<0.01	3.33	1.08-10.29	0.04
LOWER ACTIVITY LIMITATIONS (SIS)	0.99	0.67-1.02	0.65	1.00	0.97-1.03	0.95	0.92	0.89-0.96	<0.01	0.91	0.87-0.96	<0.01	1.03	0.98-1.06	0.30
LOWER FUNCTIONING OF BALANCE (BBS)	0.96	0.88-1.05	0.36	1.01	0.94-1.09	0.75	0.77	0.66-0.90	<0.01	0.64	0.50-0.81	<0.01	1.03	0.95-1.13	0.47

LPA= Light physical activity, MVPA= Moderate to vigorous physical activity, WMSB= Weighted median sedentary bout length, OR=odds ratio, CI= confidence interval, PT= physiotherapy. Age, less severe stroke symptoms, lower activity limitations and balance were analyzed as continues variables. NIHSS = National Institutes of Health Stroke Scale, MOCA= Montreal Cognitive Assessment, HADS-D= Hospital Anxiety and Depression Scale depression subscale, HADS-A= Hospital Anxiety and Depression Scale anxiety subscale, m/s= meters per second, SIS= Stroke Impact Scale, BBS= Berg Balance Scale

Table 5. Associated characteristics per movement behavior pattern using multiple logistic regression

	SEDENTARY			NONMOVER (LPA)			ACTIVE (MVPA)			ACTIVE (MVPA BOUTS> 10MIN)			PROLONGER (WEIGHTED MEDIAN SEDENTARY BOUTS)		
	OR	95% P	P	OR	95% P	P	OR	95% P	P	OR	95% P	P	OR	95% P	P
INDEPENDENT VARIABLES															
PERSONAL CHARACTERISTICS															
MALE				3.35	1.39-8.08	<0.01	6.14	2.37-15.92	<0.01						
LOWER AGE (YEARS)				1.05	1.02-1.09	<0.01	1.05	1.02-1.09	<0.01						
LIVING ALONE				0.40	0.22-0.74	<0.01	8.49	2.22-32.44	<0.01						
STROKE CHARACTERISTICS															
LESS SEVERE STROKE SYMPTOMS (NIHSS)													0.87	0.77-0.99	0.03
PSYCHOLOGICAL AND COGNITIVE FACTORS															
COGNITIVE IMPAIRED (MOCA \leq 25)				2.33	1.20-4.51	0.01							5.02	1.54-16.37	<0.01
PHYSICAL FUNCTIONING															
LIMITED COMMUNITY WALKER (\leq 0.93 M/S)							0.17	0.06-0.55	<0.01				3.11	1.15-8.44	0.03
LOWER ACTIVITY LIMITATIONS (SIS)							0.94	0.90-0.98	<0.01	0.96	0.93-0.99	0.04			

LPA= Light physical activity, MVPA= Moderate to vigorous physical activity, WMSB= Weighted median sedentary bout length, OR=odds ratio, CI= confidence interval
 Age, less severe stroke symptoms and lower activity limitations were analyzed as continues variables. NIHSS = National Institutes of Health Stroke Scale, MOCA= Montreal Cognitive Assessment, m/s= meters per second, SIS= Stroke Impact Scale

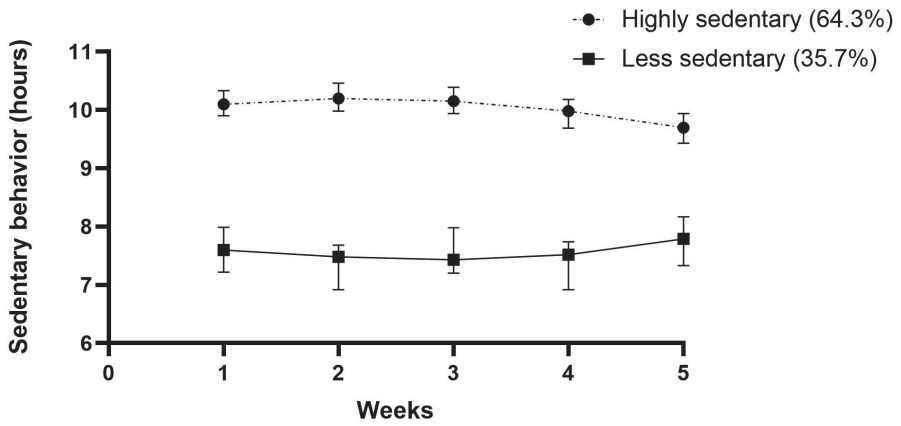


Figure 1a. Sedentary time in hours per day between three weeks and eight weeks after discharge from the hospital in stroke survivors.

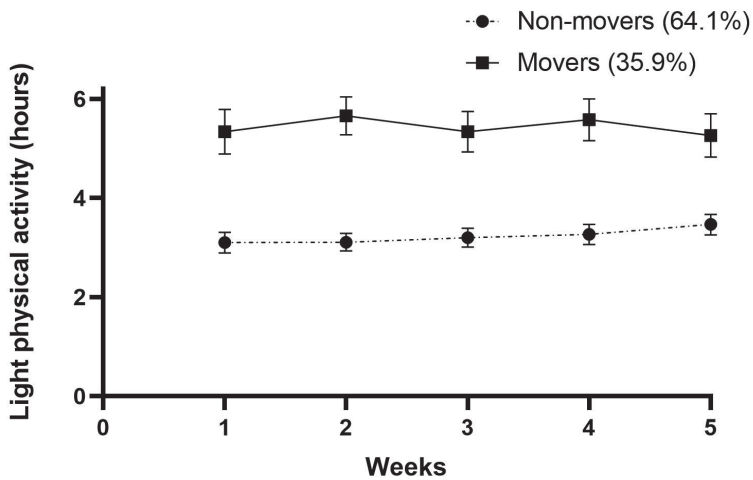


Figure 1b. Light physical activity in hours per day between three weeks and eight weeks after discharge from the hospital in stroke survivors.

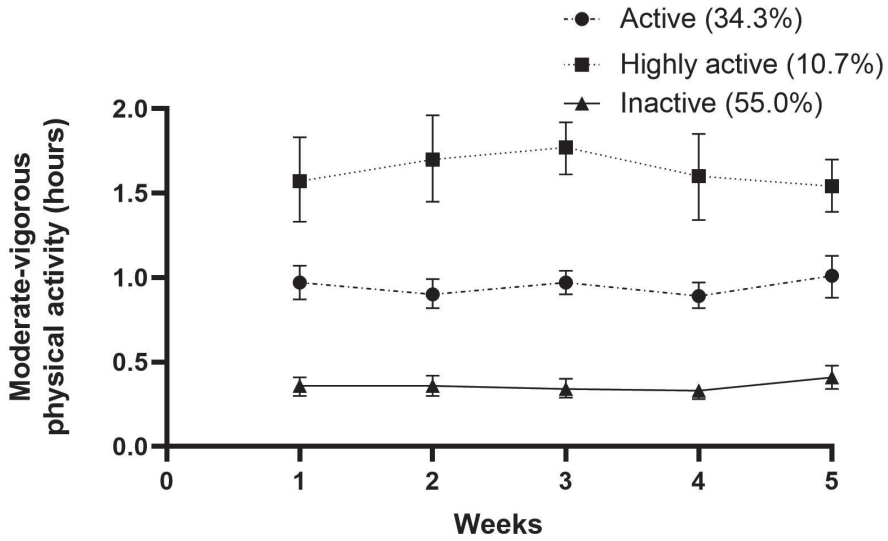


Figure 1c. Moderate to vigorous physical activity in hours per day between three weeks and eight weeks after discharge from the hospital in stroke survivors.

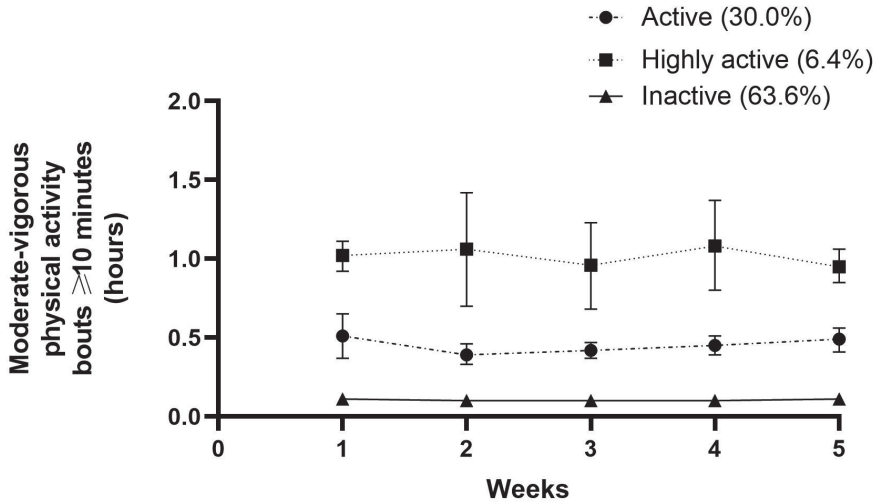


Figure 1d. Moderate to vigorous physical activity bouts (≥10 minutes) in hours per day between three weeks and eight weeks after discharge from the hospital in stroke survivors.

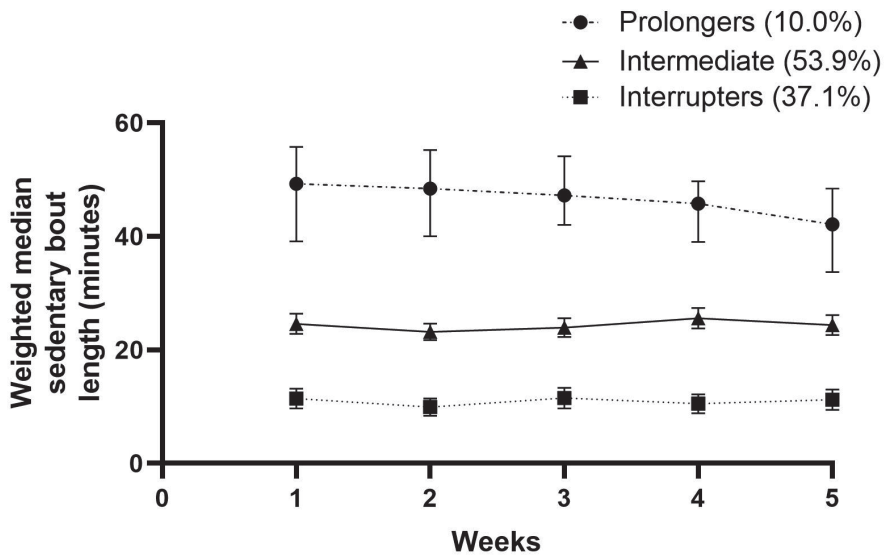


Figure 1e. Weighted median sedentary bout in minutes per day between three weeks and eight weeks after discharge from the hospital in stroke survivors.

Discussion

This study investigated changes in movement behavior outcomes and possible subgroup trajectories using objective and continuous measurement in 140 participants within the first two months after discharge from the hospital to the home setting after a first stroke. Overall, SB decreased very slightly, and LPA showed a small increase in time. Distinct subgroup trajectories were found for all movement behavior outcomes. Small changes within subgroup trajectories for SB and MVPA were found. For all other movement behavior outcomes, the identified subgroup trajectories remained stable. Individuals were distributed into different subgroups according to movement behavior outcomes. Characteristics associated with the different subgroups were explored. No associated characteristics were found regarding SB.

On average, our sample showed SB results comparable to a Dutch older adult population⁶⁵. In our sample, the majority of the people were highly sedentary, exceeding 9.5 hours. The relationship between sedentary time and mortality was more pronounced when sedentary periods exceeded 9.5 hours⁶⁶. Therefore, the reduction of SB should be a secondary prevention target for people with stroke. On average, our sample engaged in 42 minutes of MVPA per day, which is high. It is known that the Dutch population is more active than its European peers⁶⁷. In other stroke survivors, the same amount of MVPA was found (44 minutes)³⁸. Although the average amount of MVPA was high, a substantial part of the population was found to be inactive. Particularly in terms of MVPA accumulated in bouts ≥ 10 minutes.

Although a significant decrease in SB and an increase in time spent in LPA were found within the first two months after discharge, the changes were small. However, it was recently found that higher levels of physical activity, including light physical activity and less time spent in SB, reduce the risk of premature death in a dose-response manner⁶⁶. Therefore, even this small change in LPA and SB are considered relevant. Nevertheless, the absolute amount of SB was still high. A previous study (N = 10) found an increase of forty minutes in absolute activity during the day within the first six weeks after discharge to the home setting¹⁶. However, this improvement was compared to the absolute activity before discharge. When comparing activity at two weeks after discharge with activity at six weeks after discharge, an increase of only twenty minutes was found. The same increases were observed in another study regarding step count and time spent walking between one and three months after discharge¹⁷. We also found an LPA increase of twenty minutes. Therefore, it seems that after stroke, people increase their level of LPA in the short term. Regarding SB, conflicting results were found in the literature. In our sample, SB decreased while in another study with a small sample size sitting/reclining time increased¹⁷. However, in that study, sleep time was included

in the sitting/reclining time. Therefore, it remains unknown whether SB, sleep time, or both increase within the first six months after discharge to the home setting¹⁷.

The differences in the distribution and accumulation of movement behavior during the day are interesting. Over 60% of the sample was assigned to a subgroup trajectory with a mean sedentary time per day, reaching almost ten hours out of fourteen hours wear time. This indicates high amounts of SB. Prolonged bouts are more difficult to interpret since there is not a given cut-off value available yet. However, the majority of the group had a weighted median bout of over 20 minutes, indicating that over 50% of total sedentary time is spent in prolonged bouts. Interruption, after 20 minutes of SB has been found to have a positive influence on glucose levels in overweight people¹⁴.

Additionally, over 90% of the population did not reach sufficient amounts of MVPA accumulated in bouts of at least 10 minutes. Differences in the changes among the subgroup trajectories were found. Participants in the highly sedentary subgroup trajectory decreased their amount of sedentary time, and those in the inactive group increased their MVPA time. Both changes, in theory, can reduce the risk of premature death, although the changes are small⁶⁶.

Remarkably, we found no patient characteristics that were associated with highly sedentary behavior. A recent study, which pooled data from nine studies identifying associations with sedentary time after stroke, found that sedentary time could not be explained by demographic or stroke-related variables³⁰. It identified only slower walking speed as a significant factor associated with higher amounts of SB. In our sample, people were discharged immediately to the home-setting and had a relatively high walking speed, whereas the study of Hendrickx et al. included participants with a greater diversity of walking speed. This could explain why walking speed was not identified as a factor associated with SB in our sample. Although living alone was associated with the total MVPA time, it was not associated with MVPA accumulated in bouts ≥ 10 minutes. It seems that people who live alone spend time in MVPA during their ADLs and devote less leisure time MVPA in such forms as exercise or sports. More severe stroke symptoms, cognitive impairment, and not being a community walker were associated with prolongers in our study. These outcomes are in line with previous studies of people with stroke, although those studies found associations with walking speed, more severe stroke symptoms, and self-reported ADLs and sedentary bouts^{30,68}. The association between cognitive impairment and nonmovers and prolongers is interesting since no associations were found with total sedentary time or MVPA in our sample. A study including older adults found that higher amounts of SB were associated with lower cognitive function when MVPA was not taken into account; however, no association was found after adjustment for MVPA. This indicates

the importance of investigating movement behavior patterns and not just single movement behavior outcomes. Additionally, it could be that the health benefits of enough MVPA are counterbalanced by high amounts of SB.

Trajectories of single movement behavior outcomes overlap; however, they are largely unique. For example, 54% of the people who were highly sedentary were nonmovers, but only 36% of the highly sedentary people were inactive. Therefore, the next step in the research is to investigate whether movement behaviors cluster in patterns. The emergence of movement behavior patterns will provide insight into individuals' accumulation and distribution of movement behaviors during the day. Tremblay et al. described four hypothetical movement behavior patterns based on the distribution of movement behavior: 1. active and not sedentary; 2. active and sedentary; 3. inactive and not sedentary; and 4. inactive and sedentary⁷. Whether these patterns apply to the stroke population is currently unknown. Using these movement behavior patterns, individuals with unfavorable patterns of behavior can be identified. Additionally, it will be important to investigate characteristics that help to differentiate among individuals with a favorable and unfavorable movement behavior pattern. This deeper understanding of the clustering patterns could support the development of personalized interventions to improve movement behavior during waking hours⁶⁹.

Although we expected to observe more changes in movement behavior outcomes based on the efforts of health care professionals, the willingness to change because of having experienced a stroke and the fact that recovery was feasible at the time of the study, only small changes in movement behavior outcomes occurred. In this sample, 46% of the population received physiotherapy care. In general, physiotherapy care focuses on regaining physical function and improving physical fitness⁷⁰. However, improvements capabilities due to functional recovery will automatically improve ADLs, but will not automatically improve daily physical activity⁷¹ or reduce SB. Additionally, as a general practice, all people with stroke in the Netherlands are included in primary care programs in general practice. However, in these programs, there is limited attention for secondary prevention after stroke, especially physical activity^{72,73}. Additionally, changing movement behavior is a complex process and cannot be triggered by merely providing information^{74,75}. Therefore, specific interventions are needed to improve daily physical activity and decrease sedentary time. Particularly since the majority of our sample was sedentary, and a substantial part was inactive, improving movement behavior is important and needs to be targeted to counterbalance increased cardiovascular risks. Additionally, the participants in this study had relatively minor stroke symptoms but nonetheless were highly sedentary, the proportion of the sample was inactive. Although it is possible to modify daily physical activity and SB, it is not possible at present to suggest the superiority of a particular intervention approach⁷⁶.

A limitation of our study was that data regarding movement behavior during the day was obtained within three weeks after discharge. Therefore, it remains unknown whether behavioral movement changes occur within the period immediately after discharge and three weeks later. Additionally, pre-stroke movement behavior during waking hours was not obtained. Therefore, it remains unknown whether people in this sample changed their movement behavior according to the behavior in the pre-stroke period. Another limitation was that sleep time during the day was not determined, and therefore, SB may have been overestimated. Last, our study included only participants who were directly discharged to the home-setting. Since the majority of this population had minor stroke symptoms, the results are not generalizable to a more severe stroke population that received inpatient rehabilitation first. However, our findings emphasize the importance of movement behavior changes since our sample had less severe stroke symptoms but still presented high levels of SB and low levels of MVPA.

Overall, the majority of people with stroke are highly sedentary, and a substantial proportion of this population is inactive in the first two months after discharge from hospital care based on continuous objective measurement for five weeks. Furthermore, their movement behavior remains fairly stable in this period. Based on movement behavior outcomes, distinctive subgroup trajectories were found. Although the people in this study had minor stroke symptoms, they were nonetheless highly sedentary, and a substantial portion was inactive. Therefore, changes in movement behavior after discharge from the hospital are of paramount interest. Instead of providing information about changing movement behavior, personalized coaching interventions are needed. However, before such interventions take place, insight is needed into whether movement behavior during waking hours may cluster in patterns and which characteristics are related to an unfavorable movement behavior pattern in stroke survivors.

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Appendix

Table 1. Linear slopes and quadrics slopes with outcome values

	Linear slopes				quadratic slopes				
	BIC	Entropy	BLRT	Subgroup size	BIC	Entropy	BLRT	Subgroup size	
SB	1	2779.10	1.00	n.a.	140	2555.16	1.00	n.a.	140
	2	2472.68	0.89	<0.01	89/51	2343.72	0.87	<0.01	90/50
	3	2386.56	0.90	<0.01	80/41/19	2291.20	0.93	<0.01	87/52/1
	4	2278.08	0.93	<0.01	79/41/19/1	2232.75	0.92	<0.01	80/46/13/1
	5	2292.91	0.94	1.00	79/41/19/1/0	2201.08	0.90	<0.01	71/38/18/12/1
LPA	1	2630.71	1.00	n.a.	140	2372.47	1.00	n.a.	140
	2	2351.55	0.88	<0.01	90/50	2192.88	0.82	<0.01	92/48
	3	2188.71	0.94	<0.01	83/56/1	2212.64	0.89	1.00	92/48/0
	4	2186.64	0.94	1.00	81/54/5/0	2104.06	0.92	1.00	78/60/2/0
	5	2082.87	0.94	1.00	70/59/10/1/0	2123.83	0.93	1.00	78/60/2/0/0
MVPA	1	1091.74	1.00	n.a.	140	815.02	1.00	n.a.	140
	2	685.10	0.91	<0.01	96/44	537.05	0.91	<0.01	104/36
	3	504.37	0.90	<0.01	59/57/24	442.71	0.88	<0.01	77/48/15
	4	402.59	0.94	<0.01	56/55/25/4	365.09	0.92	<0.01	65/38/32/5
	5	729.58	0.96	1.00	96/44/0/0/0	366.68	0.91	<0.01	61/38/29/7/5
mvpa bout	1	401.82	1.00	n.a.	140	182.34	1.00	n.a.	140
	2	63.47	0.98	<0.01	123/17	-56.00	0.96	<0.01	121/19
	3	-83.89	0.93	<0.01	89/42/9	-143.52	0.96	<0.01	4/26/110
	4	-118.71	0.93	<0.01	87/39/10/4	-16.47	0.98	1.00	121/19
	5	-112.30	0.87	<0.01	62/39/17/13/9	3.30	0.98	1.00	121/19
median	1	5573.46	1.00	n.a.	140	5406.47	1.00	n.a.	140
	2	5299.26	0.91	<0.01	111/29	5210.83	0.94	<0.01	118/22
	3	5151.92	0.91	<0.01	74/52/14	5132.47	0.86	<0.01	71/52/17
	4	5093.48	0.90	<0.01	63/51/21/5	5087.31	0.90	<0.01	73/50/16/1
	5	5086.20	0.88	<0.01	60/45/20/10/5	5097.66	0.83	0.67	54/45/25/13/3

BIC= Bayesian information criterion, BLRT= bootstrap likelihood ratio test, SB= sedentary behavior, LPA= light physical activity, MVPA= moderate to vigorous physical activity

Statistical considerations for finding the most appropriate model included a Bayesian information criterion (BIC), entropy values and the bootstrap likelihood ratio test (BLRT). The lower the BIC score, the better the fit of the model. When BLRT was significant ($p < 0.05$), the trajectory with k-subgroups had a better fit than k-1 trajectory subgroups. The entropy statistic was used for the reliability of the subgroup trajectories. Entropy scores above 0.8 are preferred. When less than 5% of the sample was assigned to a subgroup trajectory, a k-1 subgroup trajectory was chosen in favor.

Table 2. Distribution of individuals to different subgroups per movement behavior outcome expressed in percentages

	Sedentary		LPA		MVPA		MVPA bouts ≥ 10 bouts		Weighted median sedentary bout length	
	Highly sedentary	Less sedentary	Non-movers	Movers	Inactive	Active	Inactive	Active	Prolongers	Intermediate Interrupters
Sedentary	Highly sedentary		53.6	10.7	35.7	28.6	38.6	25.7	10.0	54.3
	Less sedentary		12.1	23.6	19.3	16.4	25.0	10.7	0.0	35.7
LPA	Non-movers				37.1	28.6	39.3	26.4	10.0	55.7
	Movers				17.9	16.4	24.3	10.0	0.0	34.3
MVPA	Inactive						49.2	5.7	7.1	47.9
	active						14.2	30.7	2.9	42.1
MVPA bouts ≥ 10 bouts	Inactive								5.7	57.9
	Active								4.3	32.1
Weighted median sedentary bout length	Prolongers									
	Intermediate interrupters									

LPA= Light physical activity, MVPA= Moderate to vigorous physical activity,



CHAPTER 6



MOVEMENT BEHAVIOR PATTERNS IN PEOPLE WITH FIRST-EVER STROKE

Roderick Wondergem

Cindy Veenhof

Eveline J.M. Wouters

Rob A. de Bie

Johanna M.A. Visser-Meily

Martijn F. Pisters

Abstract

Background and Purpose

Movement behaviors, i.e., both physical activity and sedentary behavior, are independently associated with health risks. Although both behaviors have been investigated separately in people after stroke, little is known about the combined movement behavior patterns, differences in these patterns between individuals, or the factors associated with these patterns. Therefore, the objectives of this study are 1) to identify movement behavior patterns in people with first-ever stroke discharged to the home setting and 2) to explore factors associated with the identified patterns.

Methods

Cross-sectional design using data from 190 people with first-ever stroke discharged to the home setting. Movement behavior was measured over two weeks using an accelerometer. Ten movement behavior outcomes were calculated and compressed using principal component analysis. Movement behavior patterns were identified using a k-means clustering algorithm. Demographics, stroke, care, physical functioning, and psychological, cognitive, and social factors were obtained. Differences between and factors associated with the patterns were investigated.

Results

On average, the accelerometer was worn for 13.7 hours per day. The average movement behavior of the participants showed 9.3 sedentary hours, 3.8 hours of light physical activity, and 0.6 hours of moderate-vigorous physical activity. Three patterns and associated factors were identified:¹ sedentary exercisers (22.6%), with a relatively low age, few pack-years, light drinking and high levels of physical functioning;² sedentary movers (45.8%), with less severe stroke symptoms, low physical functioning and high levels of self-efficacy; and³ sedentary prolongers (31.6%), with more severe stroke symptoms, more pack-years and low levels of self-efficacy.

Conclusions

The majority of people with stroke are inactive and sedentary. Three different movement behavior patterns were identified: *sedentary exercisers*, *sedentary movers*, and *sedentary prolongers*. The identified movement behavior patterns confirm the hypothesis that an individually tailored approach might be warranted with movement behavior coaching by health care professionals.

Introduction

Globally, stroke affects 16 million individuals every year. Patients who survive a stroke are at high risk for recurrent stroke and other cardiovascular events¹. In the next decades, the prevalence of stroke is expected to increase worldwide², highlighting the need for effective disease management and secondary prevention strategies. Sufficient amounts of physical activity (PA) can reduce the risk of first-ever stroke³, risk of recurrent stroke, and other vascular events⁴.

International guidelines recommend at least 150 minutes per week of accumulated moderate-vigorous physical activity (MVPA)⁵. Only 17% of people with stroke meet these guidelines and spend only half of the recommended time being physically active compared to healthy persons^{6,7}. Therefore, stimulation of a physically active lifestyle forms a key element for secondary prevention. Furthermore, recent studies show that sedentary time in stroke survivors within the community setting ranges between 63% and 87% during waking hours. Additionally, it was found that these individuals are over one hour more sedentary than healthy persons^{6,7}. Research has also shown that even when older adults are sufficiently active, prolonged periods of sedentary behavior (SB) are independently associated with all-cause and cardiometabolic disease-related mortality⁸. Therefore, SB can also be considered an important risk factor for stroke survivors.

Recently, an international consensus was reached on a new term, “movement behavior” which includes SB and all levels of PA⁹. This term includes the daily behavior pattern of a person regarding body postures, movements, and daily activities in the person’s own environment. PA can be classified based on metabolic equivalents (METs) at three intensity levels: light PA (LPA) (>1.5-3.0 METs), moderate PA (3.0-6.0 METs) and vigorous PA (>6.0 METs). Persons are defined as physically inactive if they do not reach sufficient amounts of MVPA⁵. Notably, inactivity is not the same as SB. SB is defined as “any waking activity characterized by an energy expenditure of ≤ 1.5 METs and a sitting or reclining posture”¹⁰.

A lack of MVPA and high amounts of SB are independent risk factors for all-cause mortality, cardiovascular diseases, and functional decline^{3,4,8}. Although the independent health risks of these single behaviors are highlighted in research, these behaviors are not self-contained but cluster in patterns (e.g., high MVPA/high LPA/low SB or low MVPA/low LPA/high SB)¹¹. It could be suggested that a movement behavior pattern with sufficient MVPA, high amounts of LPA, and low amounts of SB leads to optimal health¹¹. The distribution of single movement behaviors within the total pattern is important because the health benefits of one single behavior could be counteracted by the risks of another. For example, if someone engages in at least 150 minutes per week of moderate physical activity but is sedentary for the rest

of the time, the health risks are still high⁸. Additionally, the accumulation of SB is important since long prolonged sedentary bouts are damaging health, and interrupting SB with LPA has shown cardiovascular health benefits¹².

Currently, specific movement behavior patterns in people with stroke and the associated long-term health impact are unknown. Therefore, research on the identification of commonly distinct movement behavior patterns in people with stroke is needed. Insight into movement behavior patterns in people with stroke will ultimately enable more targeted interventions in people with unhealthy movement behavior patterns (e.g., low MVPA, low LPA, and high amounts of SB). Additionally, insight into the characteristics of people with specific movement behavior patterns enables identification of the right persons for interventions after discharge from facility-based care. Therefore, the objectives of the present study were 1) to identify movement behavior patterns in people with first-ever stroke discharged from hospital or inpatient rehabilitation to the home setting and 2) to explore characteristics associated with the identified patterns.

Methods

The data that support the findings of this study are available from the corresponding author upon reasonable request

Participants and study design

Participants were recruited from four participating stroke units in The Netherlands between February 2015 and April 2017 and were included when they had returned home. Patients were deemed eligible to participate when: presenting with a clinically confirmed first-ever stroke, expected to return home (with or without inpatient rehabilitation before returning home), activities of daily living (ADL) independent before stroke (Barthel Index >18)¹³, $>$ eighteen years old, able to maintain a conversation (score > 4 on the Utrecht Communication Assessment¹⁴) and at least able to walk with supervision when they returned home (score ≥ 3 in the Functional Ambulation Categories¹⁵). Participants were excluded if their life expectancy was less than two years. All participants gave written informed consent. The study was approved by the Medical Ethics Research Committee of the University Medical Centre (UMC) Utrecht (study number 14/76). Demographic, stroke and care characteristics were obtained from medical health records. Within three weeks after discharge from inpatient care, participants were visited at home by trained researchers. Before the participant was visited at home, a postal questionnaire was sent to obtain psychological characteristics. Data on cognition, activities, and participation outcomes were obtained, and participants received an accelerometer during the visit to objectify movement behavior. The participants were given instructions to wear the accelerometer in the front pocket of their trousers on the unaffected leg, throughout the whole day during waking time. Accelerometers were worn for two consecutive weeks, after which participants sent the devices back by mail.

Dependent variables

Movement behavior was objectively measured with the Activ8, a 3-axial accelerometer (30x32x10 mm and 20 g). The Activ8 is worn on the thigh and can detect SB (lying and sitting), standing, walking, cycling, and running and yields MET values¹⁶. The Activ8 has been validated to distinguish between different postures in community ambulatory people with stroke¹⁷. Ten different movement behavior modes were calculated; mean time spent sedentary (h/d), LPA (h/d) and MVPA (h/d), mean time spent in sedentary bouts (uninterrupted periods of sitting and/or lying down) ≥ 5 minutes per day, ≥ 30 minutes per day and ≥ 60 minutes per day, mean time MVPA in bouts ≥ 10 minutes, weighted median sedentary bout length, maximum sedentary bout length and fragmentation index¹⁸. Weighted median sedentary bout length is the length of the sedentary bout corresponding to 50% of the total sedentary time¹⁸. Bouts are ordered from the shortest to the longest.

For example, if an individual has spent eight hours being sedentary, the weighted median sedentary bout length represents the length of the bout that contains the four hours' time-point. A bout length of 20 minutes would indicate that individuals engage in SB for 50% of the time in bouts ≥ 20 minutes. The lower the weighted median sedentary bout is, the more interrupted the SB. The fragmentation index is the ratio of the number of sedentary bouts ≥ 5 minutes divided by total sedentary time¹⁸. A higher fragmentation index indicates more interrupted SB. Participants filled out diaries with a start and stop time. Nonwear time was removed from the data files by comparing start and stop time from the diaries with the device's internal clock. Valid data were considered to hold at least seven days of at least 10 hours of movement behavior per day¹⁹.

Independent variables

Demographic characteristics included age, sex, educational level, living situation, body mass index, smoking (pack-years), alcohol consumption (light (0-1 drink/d), moderate (1-2 drink/d), and heavy (>2 drinks/d) drinking²⁰), PA before stroke and comorbidities. Height and weight to calculate body mass index were objectively measured, and other measures were self-reported. Educational level was asked using the Dutch classification system and dichotomized into low (score 1-5, up to completed secondary education) and high (score 6-7, completed secondary professional education, university or higher)²¹. Pre stroke physical activity was assessed with the Physical Activity Assessment scale (PAA) (range 0-8, <4 indicating insufficient amounts of MVPA). The PAA contains one question regarding moderate PA and one question regarding the amount of vigorous PA during the week²². Comorbidity was assessed by the Cumulative Illness Rating Scale (range 0-52, a higher score indicates more comorbidities)²³. Item eleven was not included because stroke is included in this item.

Stroke characteristics obtained from medical records included type, location, severity of stroke symptoms, and discharge destination. The severity of stroke symptoms was measured with the National Institutes of Health Stroke Scale (range 0-42) and was divided into 1) no stroke symptoms (0 points); 2) minor stroke symptoms (1-4 points); and 3) moderate to severe stroke symptoms (≥ 5 points)²⁴.

Balance was tested with the Berg Balance Scale (range 0-56, higher scores indicate better functioning)²⁵. Walking speed was measured with the five-meter walking test, calculated in m/s (<0.93 m/s indicating "limited community walker")²⁶. Activity limitations were assessed using the Late-Life Function and Disability Instrument Computerized Adaptive Test (LLFDI-CAT) (scores range from 0-100, and higher scores indicate better functioning)²⁷. The LLFDI-CAT contains 137 questions, which are selected based on the answer to the preceding question. The stopping rule was set for ten questions.

Cognitive functioning was assessed with the Montreal Cognitive Assessment (range 0-30; <26 indicating impaired cognitive function)²⁸. The Checklist for “individual strength – fatigue” assesses the amount of fatigue using eight items. Each item is rated on a seven-point Likert-scale (range 8-56, >40 represents severely fatigued)²⁹. Anxiety and depression were assessed with the Hospital Anxiety and Depression Scale (HADS) (range 0-21, ≥8 presence of depression or anxiety symptoms)³⁰. The HADS consists of fourteen items, seven about anxiety and seven about depression. Each question has a 4-point rating scale⁰⁻³. Self-efficacy was evaluated with the Self-Efficacy for Symptom Management Scale which consists of 13 items (range 13-130, <115 indicates low/moderate self-efficacy)³¹. Passive coping was assessed with the subscale of the Utrecht Coping List-Passive reaction pattern (range 0-28, < 16 indicates high passive coping)³², consisting of 7 questions with a four-point Likert scale. All measurement tools used were valid and reliable.

Data analysis

Data were analyzed with SPSS version 25.0. Principal component analysis (PCA) was used to compress the information on movement behavior variables to a lower subspace, resulting in components accounting for the desired variance in 60% of the data³³. Movement behavior variables were standardized using z-scores and contributed to one or more components. The compressed components were used to identify the patterns using the k-means clustering algorithm³³. K-means clustering defines that each individual can only be allocated into one pattern only by identifying cluster centers using repeated iteration. In this study, a maximum of ten iterations was used³³. The number of patterns was determined based on the interpretability of the patterns and a scree plot³³.

Descriptive variables were presented. Differences between the patterns were evaluated using ANOVA, the Kruskal-Wallis test (nonnormally distributed variables) or the chi-square test (categorical and nominal data). Post hoc analyses were performed for multiple comparisons. Differences between two patterns were evaluated with the independent t-test, a Mann-Whitney U test for non-normally distributed variables, or a chi-square test in cases of categorical and nominal data. Statistical significance was set at $p < 0.05$.

To determine factors associated with a single movement behavior pattern, logistic regression analyses were performed. Odds ratios were calculated to identify candidate factors using univariate analyses. The related variables were tested for multicollinearity (Pearson's $r < 0.70$) and effect modification (variance inflation factor > 4)³⁴. Significantly associated variables ($p < 0.1$) were entered in multiple backward logistic regression analysis.

Results

In total, 200 participants were included (see figure 1). The movement behavior data of 10 participants were missing. Therefore, 190 participants were included in the analysis. The participants' characteristics are presented in table 1. The mean age at onset of stroke was 68.1 years, 64.7% were male, 91.5% had an infarction, 54.2% had minor stroke symptoms, and 73.7% of the participants were discharged directly to the home setting.

The accelerometer was worn 90.4% of all days. The mean wear time was 13.7 hours per day. The mean sedentary time per day was 9.3 hours (67.8%), LPA 3.8 hours (27.7%), and MVPA 0.6 hours (4.6%). The weighted median sedentary bout length was 22.1 minutes, and MVPA accumulated in bouts >10 minutes was 13.8 minutes per day.

Through the use of using PCA, three components were identified, accounting for 88% of the variance. The first component (58% of the variance) included mean sedentary time, mean sedentary time in bouts ≥ 5 minutes, mean time LPA, mean sedentary time in bouts ≥ 30 minutes, and mean sedentary time in bouts ≥ 60 minutes. The second component (18% of the variance) included mean time MVPA and mean time MVPA in bouts ≥ 10 minutes, and the third component (11% of the variance) included weighted median sedentary bout length, maximum sedentary bout, and fragmentation index. Scatterplots are presented in Appendix figures 1a-c.

Three movement behavior patterns were identified. The characteristics of these patterns are presented in table 1, and movement behavior differences between individual patterns in table 2. The results of the univariate analyses per pattern are presented in Appendix Table 1. The results of the multiple logistic regression analyses per pattern are shown in table 3.

Pattern one ($n=43$; 22.6%), *sedentary exercisers*, was characterized by interrupted sedentary and active patterns. Participants assigned to pattern one were less sedentary (9.0 hours \pm 1.6), had interrupted sedentary time, and reached sufficient amounts of MVPA (0.7 hours per day in bouts ≥ 10 minutes). Factors associated were younger age, fewer pack-years, light drinking, and fewer activity limitations.

Pattern two ($n=87$; 45.8%) *sedentary movers*, was characterized by interrupted sedentary and inactive patterns. Participants assigned to pattern two showed similar results regarding total sedentary time and interrupted sedentary time but did not reach sufficient amounts of MVPA during the day (<0.5 hours per day in MVPA bouts ≥ 10 minutes). Factors associated were less severe symptoms of stroke, higher activity limitations, and higher levels of self-efficacy.

Pattern three (n=60; 31.6%), *sedentary prolongers*, was characterized by a prolonged and highly sedentary and inactive pattern. Participants assigned to pattern three were sedentary 10.7 hours \pm 1.4 per day, had long prolonged sitting bouts and insufficient amounts of MVPA during the day. Factors associated with *sedentary prolongers* were more pack-years, lower levels of self-efficacy, and more severe stroke symptoms.

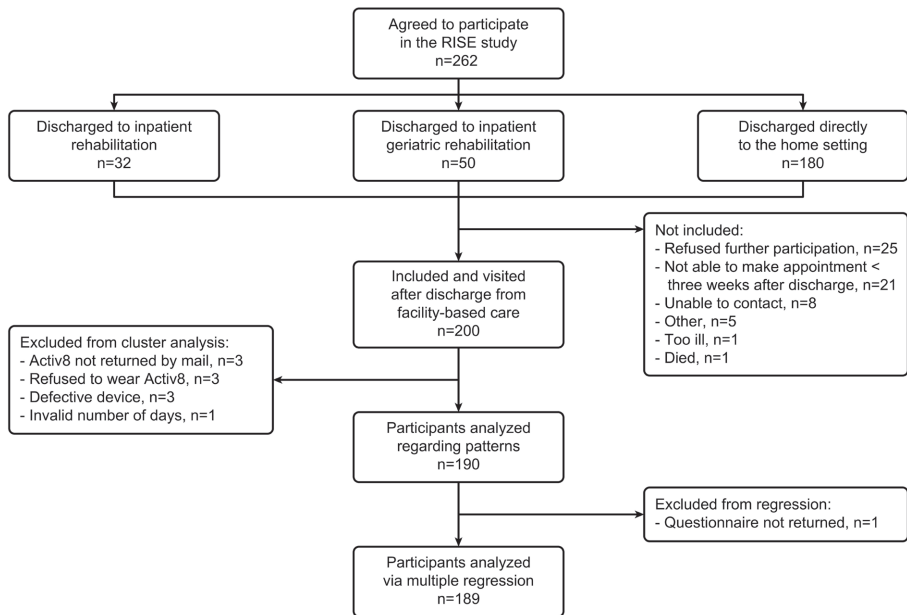


Figure I. Flow diagram of participants

Table 1. Participant characteristics and characteristics per pattern expressed as means±sd, median (IQR) or n (%)

Characteristics	Total group (n=190)	Sedentary exercisers (n=43)	Sedentary movers (n=87)	Sedentary prolongers (n=60)	p-values between groups
Demographic characteristics					
Age (years)	68.1±11.0	63.4±10.0	69.1±11.7	70.0±9.7	<0.05 ^{a,c}
Sex, male	123 (64.7)	35 (81.4)	49 (56.3)	39 (65.0)	<0.05 ^a
High education level	58 (30.5)	19 (44.2)	21 (24.1)	18 (30.0)	0.10
BMI	26.1±3.8	25.3±3.6	26.5±4.0	26.3±3.7	0.24
Pack-years	7.5 (0-30.0)	3.2 (0-18.8)	6.0 (0-27.0)	18.4 (0-34.5)	<0.05 ^{b,c}
Drinking alcohol	107 (56.3)	34 (79.1)	43 (49.4)	30 (50.0)	<0.001 ^{a,c}
Sufficient PA pre stroke	129 (67.9)	34 (79.1)	61 (70.1)	26 (43.3)	<0.001 ^{b,c}
Comorbidities (CIRS)	3 (1-5)	2 (0-4)	3 (2-5)	3 (0-5)	<0.05 ^c
Living together	145 (76.3)	31 (72.1)	64 (74.2)	50 (83.3)	0.34
Stroke characteristics					
Infarction	174 (91.6)	40 (93.0)	79 (90.8)	55 (91.7)	0.83
Side of stroke, left	100 (52.6)	25 (55.8)	42 (48.3)	34 (56.7)	0.97
Stroke severity (NIHSS)					
No symptoms (0)	26 (13.0)	6 (14.0)	13 (14.9)	7 (11.7)	
Minor stroke symptoms (1 to 4)	110 (55.0)	23 (53.5)	51 (58.6)	32 (53.3)	
Moderate to severe stroke symptoms (≥5)	64 (32.0)	14 (32.6)	23 (26.4)	21 (35.0)	0.59
Care characteristics					
Discharge destination					
Home	140 (73.7)	34 (79.1)	66 (75.9)	40 (66.7)	
Rehabilitation	23 (12.1)	4 (9.3)	10 (11.5)	9 (15.0)	
Geriatric rehabilitation	27 (14.2)	5 (11.6)	11 (12.6)	11 (18.3)	0.70
Physical functioning					
Activity limitations (LLFDI)	56.5±11.4	64.4±8.8	54.6±11.5	53.6±10.6	<0.001 ^{a,c}
Balance (BBS)	51.9±6.5	55.1±2.2	51.3±6.4	50.5±7.9	0.001 ^{a,c}
Limited community walker (<0.93 m/s)	79 (41.6)	5 (11.6)	48 (55.2)	30 (50.0)	<0.001 ^{a,c}
Psychological and cognitive factors					
Cognitive function (MOCA)					
Impaired cognition	114 (60)	27 (62.8)	51 (58.6)	36 (60.0)	0.52
Fatigue score (n=189) (CIS-f)					
Severely fatigued	71 (37.9)	11 (25.5)	31 (35.6)	29 (48.3)	0.06 ^{b,c}
Symptoms of depression	37 (18.5)	3 (7.0)	19 (21.8)	12 (20.0)	0.10 ^a
Symptoms of anxiety	34 (17.0)	10 (23.3)	16 (18.6)	8 (13.3)	0.44
Self-efficacy (n=189) (SESx)					
High self-efficacy	28 (14.7)	7 (16.3)	18 (19.5)	3 (5.6)	
Low/Moderate self-efficacy	161 (85.2)	36 (83.7)	74 (80.4)	47 (94.4)	<0.05 ^{b,c}
Passive coping (n=189) (UCL-P)	10.9±4.1	10.5±3.8	9.9±2.7	10.8±4.0	0.25
Moderate passive coping		6 (13.9)	6 (6.9)	7 (11.7)	0.39

SD= standard deviation, IQR= interquartile range, PA=physical activity, CIRS= Cumulative Illness Rating Scale, NIHSS = National Institutes of Health Stroke Scale, MI= motricity index, PT= physiotherapy, LLFDI= Late-Life Function and Disability Instrument Computerized Adaptive Test, SIS=Stroke Impact Scale, BBS=Berg Balance Scale, 5MWT= Five-Meter Walk Test, MOCA= Montreal Cognitive Assessment, m/s= meters per second, CIS-f= Checklist Individual Strength-fatigue subscale, HADS= Hospital Anxiety and Depression Scale, SESx= Self-Efficacy for Symptom Management Scale, UCL-P= Utrecht Coping List-Passive reaction pattern, SSL=Social Support List

^a statistically significant differences between patterns 1 and 2

^b statistically significant differences between patterns 2 and 3

^c statistically significant differences between patterns 1 and 3

Table 2. Participant movement behavior outcomes and movement behavior outcomes per pattern

Movement behavior outcome mean (SD)	Total group (n= 190)	Sedentary exercisers (n=43)	Sedentary movers (n=87)	Sedentary prolongers (n=60)	p-value between patterns
Sedentary behavior (hours/day)	9.3 (1.8)	9.0 (1.6)	8.4 (1.5)	10.7 (1.4)	<0.01 ^{b,c}
Percentage sedentary behavior	67.6 (11.1)	63.6 (8.7)	62.6 (9.9)	77.6 (5.5)	<0.01 ^{b,c}
LPA (hours/day)	3.8 (1.5)	3.8 (1.2)	4.6 (1.5)	2.7 (0.8)	<0.01 ^{b,c}
Percentage LPA	27.7 (10.8)	26.7 (8.2)	34.2 (10.2)	19.7 (5.2)	<0.01 ^{a,b,c}
MVPA (hours/day)	0.6 (0.5)	1.4 (0.4)	0.4 (0.3)	0.4 (0.3)	<0.01 ^{a,c}
Percentage MVPA	4.6 (3.5)	9.7 (2.6)	3.2 (2.1)	2.8 (1.9)	<0.01 ^{a,c}
Sedentary bouts ≥5 minutes (hours/day)	6.4 (1.7)	5.9 (1.1)	5.6 (1.3)	8.1 (1.1)	<0.01 ^{b,c}
Sedentary bouts ≥30 minutes (hours/day)	4.0 (1.7)	3.2 (1.0)	3.2 (1.0)	5.9 (1.1)	<0.01 ^{b,c}
Sedentary bouts ≥60 minutes (hours/day)	2.0 (1.4)	1.3 (0.8)	1.4 (0.8)	3.5 (1.2)	<0.01 ^{b,c}
MVPA bouts ≥10 minutes (hours/day)	0.2 (0.3)	0.7 (0.3)	0.1 (0.1)	0.1 (0.1)	<0.01 ^{a,c}
Weighted median sedentary bout length (min)	22.1 (13.6)	15.4 (7.6)	15.6 (7.4)	36.3 (13.2)	<0.01 ^{b,c}
Maximum sedentary bout (min)	134.3 (47.8)	121.1 (38.6)	114.9 (30.8)	171.9 (52.4)	<0.01 ^{b,c}
Fragmentation index	1.9 (0.3)	2.1 (0.2)	2.1 (0.2)	1.6 (0.2)	<0.01 ^{b,c}
Wear time	13.7 (1.4)	14.1 (1.5)	13.4 (1.3)	13.7 (1.6)	0.03 ^a

SD= standard deviation, LPA= light physical activity, MVPA= moderate-vigorous physical activity, min= minutes

a statistically significant differences between patterns 1 and 2

b statistically significant differences between patterns 2 and 3

c statistically significant differences between patterns 1 and 3

6

Table 3. Associated factors per movement behavior pattern using multiple logistic regression

	<i>Sedentary exercisers</i>			<i>Sedentary movers</i>			<i>sedentary prolongers</i>		
	OR*	95%	P	OR*	95%	P	OR*	95%	P
<i>Lower AGE</i>	1.049	1.007-1.094	0.023						
<i>Less severe stroke symptoms</i>				1.093	1.007-1.186	0.034	0.915	0.848-0.988	0.024
<i>fewer Pack-years</i>	1.028	1.003-1.055	0.030				0.980	0.965-0.995	0.010
<i>Light drinking</i>	3.994	1.609-9.918	0.003						
<i>Lower physical functioning</i>	0.942	0.899-0.987	0.013	1.041	1.010-1.073	0.009			
<i>Higher level of Self-efficacy</i>				3.232	1.313-7.941	0.011	0.288	0.090-0.919	0.035

* Odds ratio > 1 indicates higher odds for that particular movement pattern than both other movement behavior patterns

Discussion

This study is the first to investigate movement behavior patterns during waking hours, instead of single aspects of movement behavior. Our results indicated that the distribution of SB, as well as the accumulation of SB (interrupted or prolonged SB), LPA, and MVPA, differed during waking hours within the sample, resulting in *sedentary exercisers*, *sedentary movers* and *sedentary prolongers*. Although *sedentary exercisers* were physically active, they were still sedentary for almost ten hours per day. This finding confirms the indication that MVPA and SB are two independent behaviors. Therefore, research should focus on movement behavior patterns instead of the separate aspects of movement behavior (e.g., MVPA or SB only).

The comparison of SB between studies is difficult because, in most studies, sleeping time was included in sedentary time³⁵. However, the recently introduced definition of SB excludes sleeping time⁹. Only one study investigated SB excluding sleeping time in people with stroke³⁶; this study found eight percent more SB during waking hours than our results. However, only participants who received inpatient rehabilitation were included. Those participants had more severe stroke symptoms and had comparable characteristics and movement behavior outcomes to the *sedentary prolongers* in our sample. When comparing our results to a general older population in The Netherlands, participants in all three movement behavior patterns in our study were more sedentary than age-matched peers, especially sedentary prolongers who showed far more sedentary time³⁷. Additionally, sedentary movers and sedentary prolongers demonstrated lower levels of MVPA. In line with other literature, people with stroke in The Netherlands seem to be more sedentary and, in general, more inactive than healthy peers^{6,37}.

More research is needed regarding the accumulation of SB. Prolonged SB is an independent factor for increased health risks, but clear cut-off values are lacking³⁸. In general, it seems that the participants in this cohort, except for the *sedentary prolongers*, were interrupting their SB. As a result of the absence of MVPA, the high amount of SB, and the accumulation of their SB, *sedentary prolongers* are at high risk for adverse health consequences.

Important associating factors were found. The level of self-efficacy clearly discriminates between *sedentary movers* and *sedentary prolongers*. Therefore, lower self-efficacy might be an important target for future interventions to reduce prolonged SB. A lower age was associated with the *sedentary exercisers*. Older age has been associated with low MVPA levels in people with stroke³⁹. Earlier research in an elderly population showed that age was a predictor for low MVPA levels but not for the amount of LPA⁴⁰. Therefore, although *sedentary prolongers* are older, higher levels of LPA seem to be feasible. Additionally,

sedentary prolongers had significantly more severe stroke symptoms. It seems evident that people with stroke who suffer from physical impairments have more difficulties in being physically active. However, more research is needed to explore the cause of a movement behavior pattern in people with stroke. Since the strongest associating factor with sedentary prolongers was low amounts of self-efficacy, further exploration of personal and psychological factors is needed.

To identify movement behavior patterns, ten outcomes were used based on the recommendations of Byrom et al.¹⁸. Not all ten outcomes seem to be relevant when monitoring in daily practice. SB, LPA, and MVPA should be measured to objectify the distribution during waking hours⁹. Mean time MVPA in bouts ≥ 10 minutes should be included because people are classified as active when they spend 150 minutes per week in MVPA in bouts ≥ 10 minutes, according to the World Health Organization⁵. To distinguish between prolonged and interrupted SB, the weighted median sedentary bout length seems to be the most meaningful outcome and is sensitive to change over time⁴¹.

Both the associated factors and movement behavior patterns give direction for future interventions and clinical practice. Identifying movement behavior patterns will make it possible to offer individuals physical activity options that are tailored to their needs and preferences to maximize health benefits for individuals. Health care professionals should focus on how to interrupt and decrease SB for *sedentary exercisers* and *sedentary movers* to reach an optimal level of movement behavior. In addition to reducing SB, the health benefits of MVPA should not be overlooked. *Sedentary movers* should be encouraged to reach sufficient amounts of MVPA, and *sedentary exercisers* should maintain their MVPA levels. For *sedentary prolongers*, a focus on interrupting and decreasing SB seems to be a more achievable goal. Changing sedentary daily routines with at least LPA, for example, walking in their own environment or making their own coffee, could lead to a reduction in SB. Personalized movement behavior profiling is essential to tailor future coaching interventions. Since behavioral change is needed, interventions should be theory-driven and include at least important behavior change techniques such as self-monitoring of behavior, personalized feedback within the context of the individual, and action planning⁴².

A strength of our study was the use of a thigh worn accelerometer that allowed detailed analyses and identification of movement behavior patterns. Participants wore the device for fourteen days. This method accurately reflected the habitual movement behavior of people with first-ever stroke. In general, our sample had slow to normal waking speeds. A previous study found that the Activ8 is a valid measurement tool for a free-living population comparable to our sample¹⁷. Therefore, the results derived from the Activ8 are reliable and accurate. We investigated movement behavior as time spent sedentary, in LPA and in

MVPA. These movement behavior outcomes are based on METs, and these measures were determined in healthy people. Therefore, it could be that LPA levels were overestimated, and MVPA levels were underestimated⁴³. However, in one study, no significant differences in energy expenditures were found between people with stroke and healthy controls when using self-selected speeds⁴⁴. These findings indicate that classification during the day was probably correct, as most people walk at a self-selected speed. Additionally, participants in our study mainly had mild stroke symptoms supporting the hypothesis that the estimated levels of PA are probably correct. Nevertheless, more research is needed regarding energy expenditure and the intensity of MVPA in people with stroke⁴³.

Conclusion

The majority of people with stroke are inactive and sedentary. Three different movement behavior patterns in people with stroke were identified: *sedentary exercisers*, *sedentary movers*, and *sedentary prolongers*. The identified movement behavior patterns confirm the hypothesis that an individually tailored approach might be warranted with movement behavior coaching by health care professionals, based on objectively monitoring the individuals' movement patterns and associated factors.

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Appendix

Table 1. Associated factors with sedentary exercisers, sedentary movers and sedentary prolongers using univariate analyses

INDEPENDENT VARIABLES	SEDENTARY EXERCISERS				SEDENTARY MOVERS				SEDENTARY PROLONGERS			
	OR	95% CI	P- value		OR	95% CI	P- value		OR	95% CI	P- value	
PATIENT/ STROKE CHARACTERISTICS												
LOWER AGE	1.05	1.02-1.09	≥0.001		0.98	0.96-1.01	0.24		0.98	0.95-1.01	0.11	
MALE	2.93	1.27-6.77	0.01		0.51	0.38-0.93	0.03		1.02	0.54-1.93	0.96	
INFARCTION	1.29	0.35-4.77	0.70		0.83	0.30-2.32	0.72		1.02	0.34-3.07	0.98	
LEFT OF STROKE	1.10	0.65-1.87	0.73		0.87	0.56-1.35	0.53		1.09	0.68-1.76	0.72	
MORE SEVERE STROKE SYMPTOMS	1.02	0.93-1.11	0.70		1.05	0.98-1.13	0.17		0.94	0.87-1.01	0.07	
HIGH EDUCATION LEVEL	2.17	1.07-4.40	0.03		0.58	0.31-1.09	0.09		0.95	0.49-1.86	0.89	
LIVING TOGETHER	0.75	0.35-1.62	0.46		0.76	0.39-1.48	0.41		1.84	0.84-4.03	0.13	
PHYSICAL INACTIVITY PRE STROKE	0.49	0.22-1.11	0.09		0.90	0.43-1.48	0.47		2.14	1.12-4.07	0.02	
FEWER PACKYEARS	1.02	1.00-1.05	0.03		1.00	0.99-1.01	0.86		0.99	0.97-1.00	0.04	
LOWER BMI	1.08	0.99-1.19	0.10		0.96	0.89-1.04	0.29		0.99	0.91-1.07	0.72	
LIGHT ALCOHOL	3.83	1.72-8.55	≥0.001		0.60	0.33-1.06	0.08		0.69	0.37-1.27	0.23	
LESS COMORBIDITIES	1.20	1.04-1.39	0.01		0.91	0.82-1.01	0.07		0.98	0.88-1.10	0.75	
PHYSICAL FUNCTIONING												
LOWER FUNCTIONING OF BALANCE	0.73	0.61-0.88	≥0.001		1.03	0.98-1.08	0.23		1.05	1.00-1.10	0.06	
NONCOMMUNITY WALKER	0.15	0.06-0.40	≥0.001		1.58	0.88-2.84	0.13		1.96	1.05-3.64	0.04	
LOWER ACTIVITY LIMITATIONS	0.91	0.87-0.94	≥0.001		1.03	1.00-1.06	0.04		1.03	1.01-1.06	0.02	
PSYCHOLOGICAL AND COGNITIVE FACTORS												
HIGHER LEVEL OF SELF-EFFICACY	0.98	0.97-1.00	0.06		2.06	0.91-4.68	0.08		0.31	0.10-0.95	0.04	
PASSIVE COPING	0.98	0.89-1.08	0.70		1.20	0.66-2.16	0.56		0.65	0.35-1.21	0.17	
SEVERELY FATIGUED	1.04	1.02-1.07	≥0.001		0.99	0.97-1.01	0.32		1.97	1.05-3.68	0.03	
COGNITIVE IMPAIRED	0.86	0.43-1.73	0.67		1.11	0.62-1.99	0.72		1.00	0.54-1.87	1.00	
ABSENCE DEPRESSION	3.59	1.04-12.40	0.04		0.60	0.29-1.27	0.18		0.82	0.38-1.80	0.62	

OR=Odds ratio, CI= confidence interval

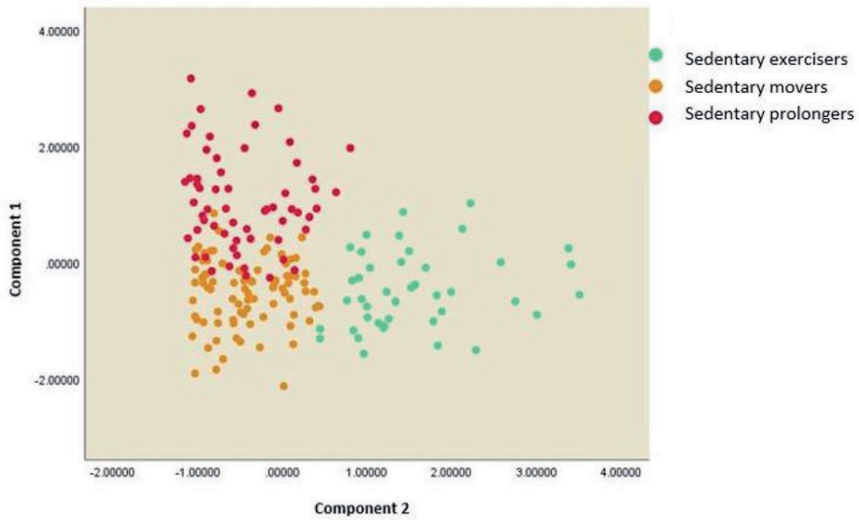


Figure 1a. Graph in two dimensions presenting the first and second components per movement behavior pattern. Component 1 represents the mean sedentary time (hours per day), mean sedentary time in bouts ≥ 5 minutes per day, mean LPA per day in hours, mean sedentary time in bouts ≥ 30 minutes per day and mean sedentary time in bouts ≥ 60 minutes per day. Component 2 represents the mean MVPA per day in hours and mean MVPA in bouts ≥ 10 minutes.

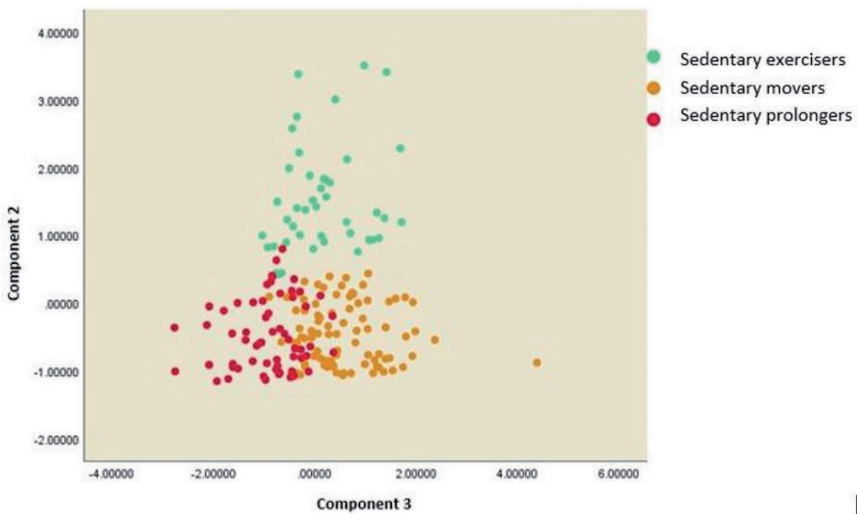


Figure 1b. Graph in two dimensions presenting the second and third components per movement behavior pattern. Component 2 represents the mean MVPA per day in hours and mean MVPA in bouts ≥ 10 minutes. Component 3 represents the weighted median sedentary bout length, maximum sedentary bout, and fragmentation index.

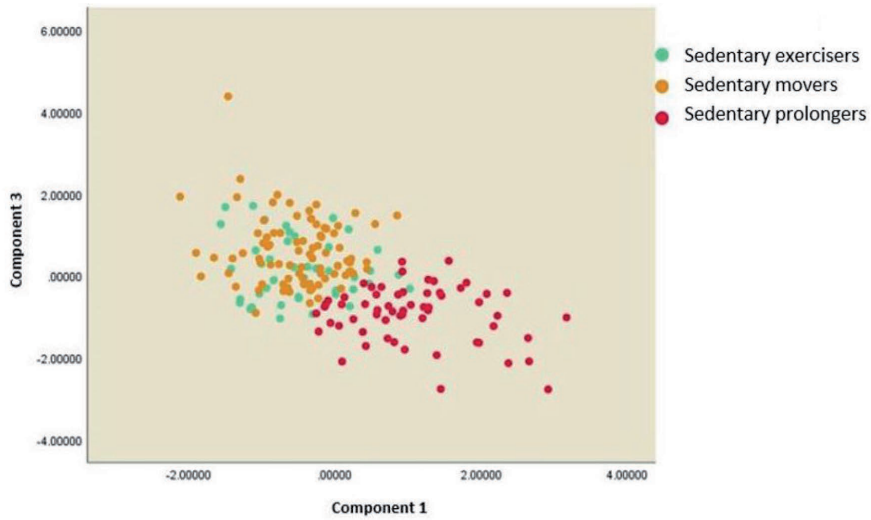


Figure 1c. Graph in two dimensions presenting the first and third components per movement behavior pattern. Component 3 represents the weighted median sedentary bout length, maximum sedentary bout, and fragmentation index. Component 1 represents the mean sedentary time (hours per day), mean sedentary time in bouts ≥ 5 minutes per day, mean LPA per day in hours, mean sedentary time in bouts ≥ 30 minutes per day and mean sedentary time in bouts ≥ 60 minutes per day.



CHAPTER 7



THE COURSE OF PHYSICAL FUNCTIONING IN THE FIRST YEAR AFTER STROKE DEPENDS ON PEOPLES INDIVIDUAL MOVEMENT BEHAVIOR PATTERN

Roderick Wondergem

Martijn F. Pisters

Eveline J.M. Wouters

Rob A. de Bie

Cindy Veenhof

Johanna M.A. Visser-Meily

Submitted

Abstract

Background

There is a growing interest in the optimal distribution of sedentary behavior and physical activity levels in people with stroke. In a previous study, three different movement behavior patterns were identified: 1. '*sedentary exercisers*' (sufficient active and sedentary 64%), 2. '*sedentary movers*' (inactive and sedentary 63%), and 3. '*sedentary prolongers*' (inactive and sedentary >78%). Currently, it is unknown if the course of physical functioning depends on movement behavior patterns.

Objective

Investigate the association between movement behavior patterns and the course of physical functioning within the first year after returning home after a stroke.

Method

A longitudinal cohort study in which 200 persons were included with a first-ever stroke discharged to the home-setting. Participants' physical functioning was assessed within three weeks, at six months, and one year after discharge. Physical functioning was subjectively measured with the Stroke Impact Scale (SIS) 3.0 and objectively with the five-meter walk test (5MWT). The association between movement behavior patterns and the course of physical functioning was determined using longitudinal generalized estimating equations analyses.

Results

Physical functioning remained stable during the first year after stroke in '*sedentary exercisers*'. Physical functioning measured with the SIS improved during the first six months after discharge in '*sedentary movers*' and '*sedentary prolongers*' and deteriorated in the following six months. A similar pattern was observed measured with the 5MWT, due to individual diversity changes showed no significance.

Conclusion

The course of physical functioning in the first year after stroke depends on people's individual movement behavior pattern.

Introduction

There is a growing interest in the optimal distribution of sedentary behavior (SB) and physical activity (PA) levels in people with stroke^{1,2}. It has been noted that people with stroke are highly sedentary and have insufficient amounts of PA^{2,3}. The composition of SB and all levels of PA (e.g., light, moderate, and vigorous) during waking hours is called movement behavior⁴. SB is defined as “any waking activity characterized by an energy expenditure of ≤ 1.5 metabolic equivalents (METs) and a sitting or reclining posture”⁴. PA is classified based on METs, in which light (LPA, 1.5-3.0 METs), moderate (MPA, 3.0-6.0 METs) and vigorous PA (VPA, > 6.0 METs) levels are distinguished. The classes moderate and vigorous are often merged as moderate to vigorous physical activity (MVPA)⁵. Movement behavior differs per individual and reflects the total habitual behavior during waking hours.

Single aspects of movement behavior, e.g., SB, LPA, and MVPA, are not self-contained and cluster in patterns. Recently, our research group investigated movement behavior patterns, and three different movement behavior patterns were identified in people with stroke: *sedentary exercisers (23%)*, *sedentary movers (46%)*, and *sedentary prolongers (32%)*³. Sedentary exercisers were sedentary for 64% of their waking hours and spent 27% of their waking hours in LPA and 10% in MVPA. Sedentary movers were 63% of their waking hours sedentary, spent 34% in LPA, and 3% in MVPA. Both sedentary exercisers and sedentary movers interrupted their SB frequently. The third pattern, sedentary prolongers, were highly sedentary (78%), spent 20% of their time in LPA, and 2% in MVPA. Sedentary prolongers spent their sedentary time in long prolonged sedentary bouts.

Physical functioning after stroke is an essential determinant for social reintegration, and deterioration of physical functioning is regarded as a major problem as it could lead to dependency in daily life and participation restrictions⁶⁻⁸. Over fifty percent of people with stroke report longer-term problems with aspects of physical functioning like mobility and falls⁹. Physical functioning declines over time after stroke in a substantial part of the population. Over 25% of all people with stroke decline in physical functioning within the first year after stroke compared with the highest level reached after stroke⁶, increasing to forty percent in the first three years after the event¹⁰. Physical inactivity was found to be associated with a decline in physical functioning in people with stroke¹⁰. In an older adult population, high amounts of SB was related to a decline in physical function¹¹. In people with stroke, research is lacking regarding the relationship between SB and physical functioning. Moreover, the relationship between movement behavior patterns and the course of physical functioning over time is not clear.

Investigating this relationship will provide insight if the course of physical functioning depends on the movement behavior pattern of the person with stroke. If the course of physical functioning depends on the movement behavior pattern, people with an unfavorable movement behavior pattern might benefit from specific movement behavioral interventions to prevent the decline of physical functioning. Therefore, the aim of this study is 1) to describe the course of physical functioning during the first year after returning home in people with a first-ever stroke, 2) to describe the course of physical functioning per movement behavior pattern, and 3) to determine the association between movement behavior patterns and the course of physical functioning during the first year after stroke.

Methods

The RISE longitudinal cohort study holds 200 persons with a first-ever stroke who are being discharged to the home-setting. Participants from four stroke units in The Netherlands were included between February 2015 and April 2017. Eligible participants were asked by their clinician to participate if they had a clinically confirmed first-ever stroke and were discharged directly to their own home setting. They should have been activities of daily living(ADL) independent before stroke (Barthel index score $>18^{12}$), over eighteen years old, able to keep a conversation going (Utrecht Communication Assessment score $>4^{13}$) and at least able to walk with supervision after stroke (Functional Ambulation Categories score $>2^{14}$). People with subarachnoid hemorrhage were excluded. Written informed consent was obtained at the stroke unit. The study was approved by the Medical Ethics Research Committee of the University Medical Centre Utrecht (study number 14/76). After written, informed consent was obtained, demographic, stroke and care characteristics were extracted from patients' records. Participants were visited within three weeks, after six months, and one year after returning home. Physical functioning outcomes were obtained during the visits, and participants were asked if they received physiotherapy care. After each visit, participants wore an accelerometer for fourteen days.

Physical Functioning

Physical functioning was measured with the subdomain physical functioning of the Stroke Impact Scale (SIS) 3.0^{15,16} and the five-meter walking test (5MWT). Subdomains of the SIS 3.0 can be evaluated separately and show excellent validity¹⁷. The subdomain physical functioning consists of ten questions regarding ADL, eight regarding mobility, and five regarding hand function^{15,16}. As recommended, scores were calculated to percentages of the total amount of points, resulting in a range from 0 to 100. Lower scores indicate lower levels of physical functioning.

Performance-based limitations in activities were measured using the 5MWT¹⁸. Participants were asked to perform this test three times. The mean walking test time was calculated. Because it was not possible to perform the 10-meter walking test in some of the participants' residences, the 5MWT was chosen. The 5MWT has the same psychometric properties as the 10 MWT¹⁸: the more time it takes, the more limitations in activities.

Movement behavior

In the current study, participants are classified in three different movement behavior pattern groups, as identified in earlier research by our group³; '*sedentary exercisers*', '*sedentary movers*', and '*sedentary prolongers*'. The same cohort is used in the current study. In the previous study movement behavior patterns were identified using principal component

and cluster analysis using relevant movement behavioral variables as recommended by Byrom et al. (e.g. ,behavior mean time spent sedentary (h/d), LPA (h/d) and MVPA (h/d), mean time spent in sedentary bouts (uninterrupted periods of sitting and/or lying down) ≥ 5 minutes per day, ≥ 30 minutes per day and ≥ 60 minutes per day, mean time MVPA in bouts ≥ 10 minutes, weighted median sedentary bout length, maximum sedentary bout length, and fragmentation index)¹⁹.

Movement behavior was measured using the Activ8 accelerometer, which has been validated in community living ambulatory people with stroke²⁰. The Activ8 is a thigh worn three-axial accelerometer. Participants got clear wearing instructions and registered wearing time on an activity log for fourteen days. The Activ8 measures different postures and corresponding MET values. The Activ8 measures with a frequency of 12,5 Hz, with a sample interval of five seconds, and stores every five minutes a summary of the different postures and MET values²¹. In this study, five movement behavior outcomes were presented at baseline: mean time of SB, LPA, MVPA, MVPA accumulated in bouts ≥ 10 minutes, and weighted median sedentary bout length. Mean time spent in SB, LPA and MVPA give insight into the distribution of movement behavior during waking hours. MVPA accumulated in bouts ≥ 10 minutes accounts for a sufficient amount of physical activity²². Therefore, the mean MVPA time accumulated in bouts ≥ 10 minutes was calculated as 10 or more consecutive MVPA minutes, with allowance for interruptions of no more than 2 minutes²³. To investigate prolonged SB, the weighted median sedentary bout length was calculated. The weighted median sedentary bout is the sedentary bout that corresponds to 50% of the total sedentary time¹⁹.

Demographic and stroke characteristics

Age, sex, and physiotherapy care was obtained from the medical record of the participant. Physiotherapy care after stroke was inventoried by asking the participant and/or relative during baseline, six months, and twelve months after discharge if they had received physiotherapy. Stroke severity was measured with the National Institutes of Health Stroke Scale (range 0-42) and was divided into: 1) no stroke symptoms (0 points); 2) minor stroke symptoms (1-4 points); and 3) moderate to severe stroke symptoms (≥ 5 points)²⁴(²⁵).

Statistical analyses

Normality assumption was checked by comparing histograms to a normal probability curve. Multiple imputation was performed using Multivariate Imputation by Chained Equation. Participants with incomplete data were more often female, which means that missing data depended on other observed data. Therefore, the missing at random method behavior was used²⁶. Multiple imputation was performed by fitting models to predict missing physical functioning outcomes based on all other observed variables, including descriptive and

movement behavior outcomes. Five imputed data sets were created and combined with a pooled set using Rubin's rules²⁷.

To study the course of physical functioning in the entire sample and per movement behavior pattern, longitudinal analyses using generalized estimating equations (GEEs) were performed²⁸ using an exchangeable correlation structure²⁸. Two time periods were examined; from discharge to six months and from six months to one year since recovery patterns are known to increase up to six months²⁹. For each outcome, a GEE was created to examine the course during each time period. Stroke severity, age, sex, and receiving physiotherapy care were added to all models to examine the possible confounding effect of these factors.

GEE analyses were performed to determine the association between movement behavior patterns and the course of physical functioning during the first year after stroke³. Per physical functioning outcome, a GEE analysis was performed. Physical functioning outcome was set as the dependent variable, and movement behavior pattern served as the independent variable. Stroke severity, age, sex, and receiving physiotherapy care or not were added to all models to adjust for confounding effects. Sedentary exercisers were set as a reference to investigate the association of change in physical functioning compared to sedentary prolongers and sedentary movers. Results are expressed as regression coefficients (B) with 95% CI's. A negative score implies a decline in physical functioning compared to sedentary exercisers with B units per time period (six months). P-values are given to objectify differences between the associations with a change of time between sedentary exercisers, sedentary movers, and sedentary prolongers.

P-values of < 0.05 were considered to be statistically significant. All analyses were carried out using SPSS (version 25.0; IBM corp.; Armonk NY)

Results

A total of 262 people from the stroke-unit agreed to participate in the study. In total, 200 participants were included and analyzed. The flow-chart and reasons for refusal are presented in figure I. At six months, 184 (92%) people participated in the study and 175 (88%) after one year. A total of 171 (86%) participants had complete data.

Table 1 presents baseline characteristics for the entire study sample after imputation of missing data. Mean age of the entire sample was 67.8 (SD 11.2) years. The majority of the population was male (64.8%), 68.5% had no or minor severe stroke symptoms, and 73.5% was discharged directly to the home-setting. Sedentary exercisers spent significantly more time in MVPA compared to the other two movement behavior patterns. Sedentary movers spent more time in LPA compared to the other two. Sedentary prolongers were more sedentary and spent less time in physical activity compared to the other two. Differences between participants allocated to the different movement behavior patterns can be found in table 1.

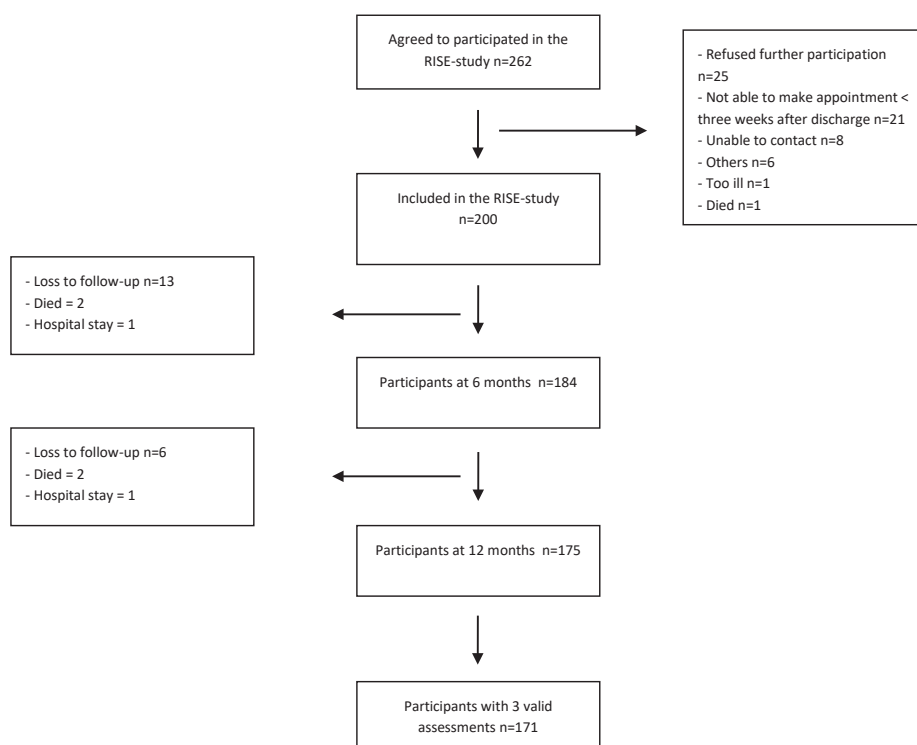


Figure I. RISE - Study flow-chart

Table 1. Baseline characteristics

	Total group n = 200	Sedentary exercises n = 44 (22%)	Sedentary movers n = 91 (46%)	Sedentary prolongers n = 65 (32%)
Demographic factors				
Sex (male)	64.0	81.8	56.0 ^a	63.1
Age (years)	67.8±11.2	63.4±10.0	68.5±12.1 ^a	70.0±9.7 ^c
Living together	76.3	72.7	74.4	71.9
Education level (high)	29.8	43.2	24.4	28.1
Stroke factors				
Ischemic stroke	91.5	93.2	91.2	90.8
Left Hemisphere	53.5	56.8	50.5	55.4
Stroke Severity (NIHSS)				
No stroke symptoms (0)	13.0	13.6	14.3	10.8
Minor stroke symptoms (1-4)	55.5	52.3	59.3	52.3
Moderate to severe stroke symptoms (>4)	31.5	34.1	26.4	36.9
Cognitively impaired (MOCA≤25)	59.0	61.4	58.2	58.5
Discharge destination				
Home	73.5	79.5	75.8	66.2
Rehabilitation	12.0	9.1	12.1	13.8
Geriatric rehabilitation	14.5	11.4	12.1	20.0
Sedentary time (hours)	9.25 [9.01-9.50]	8.99 [8.52-9.45]	4.57[4.26-4.87]	0.40[0.34-0.47] ^c
LPA (hours)	3.81 [3.61-4.02]	3.76 [3.43-4.10]	0.44[0.38- 0.49] ^a	0.13[0.10-0.17] ^c
MVPA (hours)	0.63 [0.56-0.69]	1.34[1.24-1.45]	0.11[0.08-0.13] ^a	35.94[32.79-39.09] ^{b,c}
MVPA bouts ≥ 10 minutes (hours)	0.23 [0.21-0.27]	0.65[0.55-0.74]	16.16[14.57-17.75]	
WMSB (minutes)	22.51 [20.64-24.38]	15.81[13.49-18.12]		

Values are percentage or mean ± SD

NIHSS= National Institutes of Health Stroke Scale; MOCA, Montreal Cognitive Assessment; MOCA= Montreal Cognitive Assessment, LPA= light physical activity, MVPA= moderate-vigorous physical activity, WMSB= Weighted median sedentary bout length

^a statistically significant differences between patterns 1 and 2

^b statistically significant differences between patterns 2 and 3

^c statistically significant differences between patterns 1 and 3

The course of Physical functioning and Movement behavior

Table 2 presents physical functioning outcomes for the entire sample at baseline and the change scores between baseline and six months and between six and one year. Significant improvements between baseline and six months were found for all physical functioning outcomes. All physical functioning outcomes, except SIS-ADL, decreased significantly between six months and one-year follow-up.

Table 2. The course of physical functioning in the first year after discharge to home setting within the entire sample.

	Baseline Mean [95% CI]	Mean change scores [95% CI] 6 months follow-up	Mean change scores [95% CI] 6 to 12 months follow-up
SIS physical functioning	83.94 [81.55-86.34]	3.30 [1.97-4.63]*	-2.20 [-3.19- -1.21]*
SIS - ADL	85.24 [82.96-87.52]	3.78 [2.48-5.08]*	-1.18 [-2.23- 1.14]
SIS - Mobility	83.49 [81.00-85.98]	1.97 [0.24-3.70]*	-2.91 [-4.25- -1.57]*
SIS – Hand Function	82.18 [78.59-85.76]	4.74 [2.65- 6.83]*	-2.94 [-4.71- -1.17]*
Timed walking test (5MWT)**	6.01 [5.55-6.47]	-0.46 [-0.71- -0.20]*	0.36 [0.07-0.65] *

SIS= Stroke impact scale; ADL= Activities of daily living; 5MWT= five meter walking test

Physical functioning outcomes are adjusted for stroke severity, age, sex and receiving physiotherapy care.

* statistically significant change

** a negative change means less limitations in activities

The course of physical functioning per movement behavior pattern

Table 3, figure II and figure III present the course of physical functioning per movement behavior pattern. At baseline, six months and one-year physical functioning outcomes differ between sedentary exercisers and the two other movement behavior patterns. No significant difference was found at baseline between sedentary movers and sedentary prolongers (see Figures II and III). At six months and one year after discharge, the scores of SIS physical functioning were significantly different between sedentary movers and sedentary prolongers, whereas sedentary movers had higher outcomes (see figure II). Additionally, the outcomes of the 5MWT were different in favor of sedentary movers after one year (see figure III).

Physical functioning outcomes in sedentary exercisers remained relatively stable during the first year after discharge.

All physical functioning outcomes improved between discharge and six months in sedentary movers. However, between six months and one year after discharge, a decrease in SIS physical functioning, mobility, and hand function was observed.

Sedentary prolongers improved in SIS physical functioning, ADL, and hand function scores in the first six months after discharge. However, between six months and one-year physical functioning outcomes deteriorated significantly. Additionally, SIS mobility declined significantly between six and twelve months.

Table 3. The course of physical function from baseline to six months and from six months to one year per movement behavior pattern.

	Sedentary exercisers			Sedentary movers			Sedentary prolongers		
	Baseline outcome [95%CI]	Mean change [95%CI] between baseline and 6 months	Mean change [95%CI] between 6 and 12 months	Baseline outcome [95%CI]	Mean change [95%CI] between baseline and 6 months	Mean change [95%CI] between 6 and 12 months	Baseline outcome [95%CI]	Mean change [95%CI] between baseline and 6 months	Mean change [95%CI] between 6 and 12 months
SIS Physical functioning	94.27 [92.29-96.25]	1.09 [-0.26-2.43]	-0.81 [-2.26-0.65]	82.91 [79.47-86.35]	4.84 [2.72-6.96]*	-1.88 [-3.16- -0.61]*	78.40 [73.60-83.20]	2.64 [0.06-5.22]*	-3.57 [-5.79- -1.35]*
SIS - ADL	95.40 [93.70-97.10]	1.34 [-0.21-2.89]	-0.41 [-1.83-1.01]	84.09 [80.88-87.30]	5.92 [3.81-8.03]*	-0.63 [-1.93-0.68]	79.96 [75.30-84.62]	2.44 [0.13-4.75]*	-2.49 [-4.93- -0.04]*
SIS - Mobility	94.00 [91.83-96.17]	-0.01 [-1.81-1.79]	-0.91 [-3.20-1.38]	82.63 [79.00-86.26]	3.10 [0.42-5.78]*	-2.96 [-4.79- -1.13]*	77.56 [72.66-82.47]	1.73 [-1.83-5.28]	-4.19 [-6.98- -1.40]*
SIS - Hand Function	92.50 [88.18-96.83]	2.57 [-0.58-5.72]	-1.41 [-4.00-1.18]	81.04 [75.91-86.18]	5.82 [2.64-9.01]*	-2.46 [-4.61-0.31]*	76.77 [69.35-84.19]	4.69 [0.63-8.76]*	-4.63 [-8.79- -0.48]*
Timed walking test (5MWT)	4.49 [4.28-4.71]	-0.16 [-0.35-0.04]	0.11 [-0.08-0.31]	6.06 [5.38-6.74]	-0.56 [-0.94- -0.17]*	0.28 [-0.02-0.59]	6.96 [5.99-7.92]	-0.52 [-1.06-0.03]	0.63 [-0.14-1.41]

A negative change score for the five meter walking test means an increase in function and less seconds means better performance. A positive change score means an increase in function for the SIS, higher scores indicate higher physical functioning.

B= unstandardized coefficient; CI=confidence interval; SIS= Stroke impact scale; ADL= Activities of daily living; 5MWT= five meter walking test

* Significant change compared to previous measure

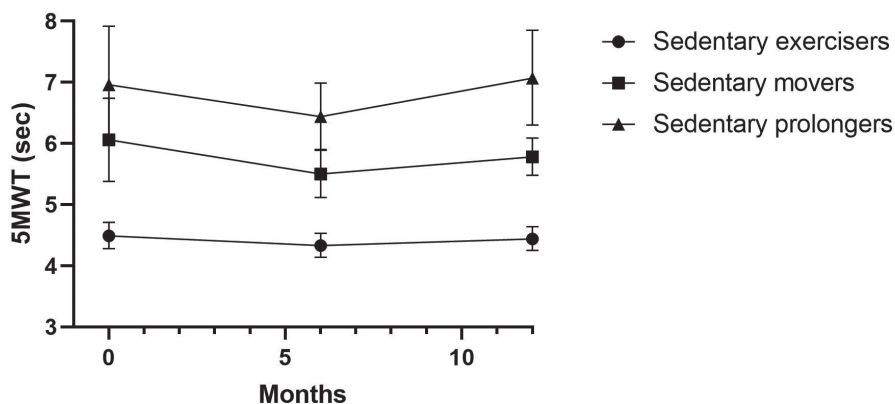


Figure II. The course of physical functioning during the first year after returning home in people with a first ever stroke per movement behavior pattern objectified with the stroke impact scale 3.0 physical functioning.

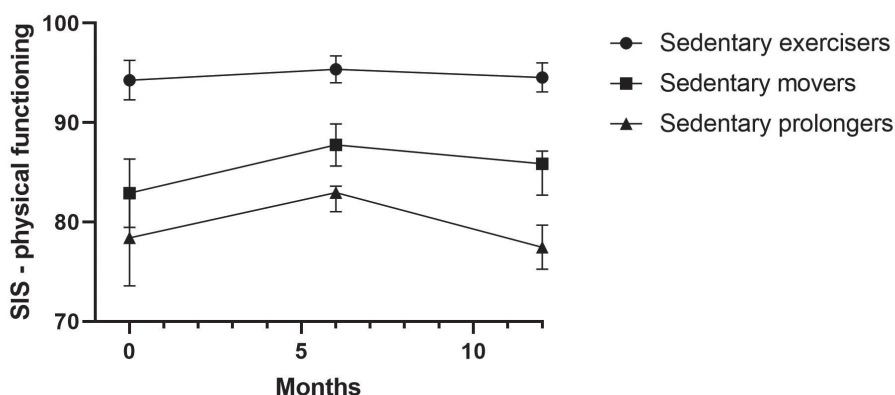


Figure III. The course of physical functioning during the first year after returning home in people with a first ever stroke per movement behavior pattern objectified with the 5 meter walk test.

The longitudinal association of physical functioning and the movement behavior patterns

Table 4 presents the results regarding the association between movement behavior patterns and the course of physical functioning during the first year after stroke. Both sedentary movers and sedentary prolongers performed significantly worse compared to sedentary exercisers. Additionally, sedentary prolongers' performed significantly worse compared to sedentary movers (SIS physical -5.03 [-9.67- -0.39]). No significant differences were found when comparing the outcomes of SIS-hand function and the 5MWT between prolongers and movers.

Table 4. The association between movement behavior patterns and the course of physical functioning during the first year after stroke using 'sedentary exercisers' as a reference.

	Sedentary exercisers B [95%CI]	Sedentary movers B [95%]	Sedentary prolongers B [95%CI]
SIS Physical functioning	108.45[99.06-117.84]	-7.05[-10.05- -4.05]*†	-12.08[-16.47- -7.68]*
SIS - ADL	104.63[96.32-112.93]	-6.47[-9.02- -3.93]*†	-12.13[-16.12- -8.14]*
SIS - Mobility	116.84[106.18-127.50]	-7.16[-10.51- -3.81]*†	-12.29[-17.17- -7.40]*
SIS – Hand Function	99.24[84.72-113.77]	-7.76[-12.57- -2.94]*	-11.20[-17.90- -4.51]*
Timed walking test (5MWT)	1.08[-0.80-2.96]]	0.91[0.42-1.41]*	1.71[0.87-2.55]*

B = coefficient in GEE analysis (Interpretation: Difference on average over time in the course of physical functioning between movement behavior patterns (comparison: sedentary movers versus sedentary exercisers & sedentary prolongers versus sedentary exercisers).; negative signs (B) indicate a decline in physical functioning. A positive score for the 5 meter walking test means an decrease in functioning.

B= unstandardized coefficient; CI=confidence interval; SIS= Stroke impact scale; ADL= Activities of daily living; MOB= Mobility; 5MWT= five meter walking test

Outcomes are adjusted for stroke severity, age, sex and receiving physiotherapy care

*Difference with sedentary exercisers P<0.01

†Difference between sedentary movers and sedentary prolongers P<0.05

Discussion

The present study showed that physical functioning increased during the first six months after discharge and decreased in the six months afterward in people with a first-ever stroke. Both the baseline scores of physical functioning and the course differ between the three movement behavior patterns. Physical functioning of the most active group, sedentary exercisers, remained fairly stable during the first year. When comparing the association between movement behavior patterns and the course of physical functioning, both sedentary prolongers and movers had unfavorable outcomes compared to sedentary exercisers. Additionally, sedentary prolongers seemed to decline more in physical functioning compared to sedentary movers over time. Highly sedentary people have an unfavorable course of physical functioning over time compared to individuals with higher amounts of physical activity.

Recovery trajectories of physical functioning in people with stroke are known from literature^{10,29}. It was found that physical functioning improves up to six months, and after the first six months, there are three trajectories: a stable trajectory, a deteriorating trajectory, and an improving one. Remarkably, in our sample, there were no improvements observed within the three movement behavior patterns after the first six months. Compared to other samples, our sample had mainly minor stroke symptoms, which could be an explanation for the lack of improvement. Another possible explanation is that we investigated mean changes in physical functioning within the specific movement behavior patterns. Given the wide confidence intervals, there are differences on the individual level, whereas mean changes do not reflect the change on the individual level. Therefore, it is plausible that on an individual level, people improved. Especially changes in the timed walking test, 5MWT, showed wide confidence intervals. Sedentary prolongers declined with 0.63 seconds on the 5MWT, which indicates a deterioration of physical functioning, after the first six months. Although this change did not show statistically significant differences, it revealed a small but meaningful change (0.3 seconds change) and almost a substantial, meaningful change (0.7 seconds change)³⁰. Moreover, it reflects the individual differences within sedentary prolongers.

Both baseline scores and the course of physical functioning differ between the movement behavior patterns. After discharge, sedentary prolongers had the lowest score, followed by sedentary movers and sedentary exercisers. Therefore, it seems that physical functioning outcomes at baseline are decisive for the course of physical functioning within the first year. Sedentary exercisers' physical functioning remained stable during the first year after stroke, while others declined after the first six months. This underlines the protective ability of sufficient amounts of MVPA since sedentary exercisers are sufficiently active, and both

sedentary movers and sedentary prolongers are inactive. MVPA is essential to improve and maintain physical fitness. Additionally, physical fitness determines our capacity to perform and tolerate physical activity and physical functioning³¹. Since sedentary prolongers had already at baseline lower physical functioning outcomes, and the course is even worse, the need for support to protect the decline in physical functioning in this group is urgent. Recently in a study with elderly adults, it was found that being less sedentary was related to less decline in physical functioning compared to elderly adults who spent more time in LPA¹¹. This is comparable to our results. Although the amount of SB in sedentary movers is high, they spent quite some time in LPA compared with sedentary prolongers. Therefore, it seems that spending more time in LPA gives better physical functioning outcomes over time. This underlines the importance of investigating movement behavior as a total compared to studies investigating only a sufficient amount of MVPA. Otherwise, the benefits of more LPA would have been overlooked. The found results in our study indicate that the course of physical functioning depends on people's individual movement behavior in the first year. However, research with a long-term follow-up is needed to prove these courses over time.

Remarkably, at baseline, only sex and age differ between the three movement behavior patterns and not stroke severity nor cognition. However, in our previous study, a weak association was found with stroke severity and sedentary prolongers³. Sedentary prolongers have lower physical functioning levels, which is not surprising given the association with stroke severity. These findings are in line with another study where stroke severity was found to be associated with greater SB³². Additionally, sedentary movers and sedentary prolongers were older compared to sedentary exercisers. This is in line with literature since older age has been associated with lower activity levels^{33,34}. More women are sedentary movers and spent more time in LPA and less in MVPA or SB. This difference was found in other studies and explained by the traditional gender roles^{33,35}. Older women are traditionally more involved in LPA household tasks compared to men in the Netherlands. In a comparable cohort, it was found that psychological factors, in particular helplessness and passive coping were predictors for unfavorable physical health-related quality of life (which is strongly correlated with the SIS-physical subscale)³⁶. Since we found low levels of self-efficacy as the strongest associating factor in our cross-sectional study, psychological factors seem to be important in the course of physical functioning.

The current approach in our health system doesn't reduce sedentary behavior nor improve physical activity levels. Both movement behaviors were found to remain stable over time^{32,37}. Therefore, sustainable behavioral change interventions to prevent a decline in physical functioning are needed. Currently, interventions regarding improving free-living MVPA (not supervised) are poorly described, and intervention studies regarding reducing SB are scarce, while studies with a follow-up after three months are completely lacking³⁸. There

is evidence that tailored counseling improves long term PA participation, especially when performed in the home setting of a person with stroke³⁹. Moreover, preliminary results of tailored interventions targeting the reduction of SB in older adults seem to be promising⁴⁰. Based on the movement behavior pattern, individuals will have different target behaviors.

This study has several strengths. This study is the first longitudinal study investigating movement behavior in all its aspects with a large sample size and using the newly introduced definition of SB, i.e., excluding sleeping time⁴. Therefore, this study truly reflects the habitual movement behavior during waking hours. Although it could be questioned whether participants modified their movement behavior due to wearing an accelerometer, there are no studies known that have reported such effects using an accelerometer for fourteen days. Therefore we have the opinion that the used method enables accurate assessment of the habitual movement behavior of the individuals.

Considering limitations, the majority of the population (>90%) had an ischemic stroke which is an overrepresentation of 15% with the stroke population in the Netherlands⁴². The explanation of the overrepresentation is that the majority of people with hemorrhagic strokes are referred to academic hospitals. Another limitation is that people with mainly minor stroke symptoms are included. It could be that people with more severe stroke symptoms were not included in our sample since these patients were not able to communicate or did not understand the information regarding this study. However, since the baseline characteristics are comparable to another large sample in the Netherlands, we believe that the results are generalizable to a population of patients with stroke discharged to the home-setting.

In conclusion, both at baseline and the course of physical functioning differ between the movement behavior patterns. Therefore, it seems that physical functioning outcomes at baseline are decisive for the course of physical functioning within the first year. The need for interventions to prevent decline in physical functioning is urgent. Therefore, tailored interventions for both *sedentary movers* and *sedentary prolongers* are needed.

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CHAPTER 8



SELECTING BEHAVIOR CHANGE TECHNIQUES TO REDUCE SEDENTARY BEHAVIOR IN PEOPLE WITH STROKE USING THE BEHAVIOR CHANGE WHEEL

Roderick Wondergem

Wendy Hendrickx

Eveline J.M. Wouters

Rob A. de Bie

Johanna M.A. Visser-Meily

Cindy Veenhof

Martijn F. Pisters

Submitted

Abstract

Background

Research has shown that sedentary behavior increases the risk of stroke, cardiovascular disease, and mortality. People with stroke are highly sedentary. Therefore, reducing sedentary behavior might reduce the risk of secondary events and death. Personalized strategies using behavioral change techniques directed at reducing sedentary behavior in people with stroke are currently lacking.

Purpose

To systematically determine the behavior change techniques (BCTs) for a behavioral change intervention directed at reducing sedentary behavior in community-dwelling people with stroke using the Behavior Change Wheel (BCW).

Method

To complete the stages of the BCW, information on understanding the behavior, identifying intervention functions, identifying BCTs, and modes of delivery were needed. To acquire this information, per stage, a literature search was conducted, and nominal group technique (NGT) sessions were conducted to identify BCTs. The NGT sessions were conducted with professionals working with people with stroke and with international researchers working in the stroke or sedentary behavior field. Participants made their choice by rating the BCTs, starting from most important (eight points) down to zero points.

Results

In total, 75 eligible BCTs were identified. Five BCTs should always be included: 'goal setting', 'action planning', 'social support', 'problem solving' and 'restructuring of the social environment'. For patients without cognitive impairments, 'self-monitoring', 'feedback on behavior', 'information about health consequences' and 'goal setting on outcome' were advised to be included, while for patients with cognitive impairments, 'prompts/cues', 'graded tasks', 'restructuring the physical environment' and 'social support practical' should be considered.

Conclusion

Behavior change techniques were identified for a behavioral change intervention aiming to reduce sedentary behavior in community-dwelling people with first-ever stroke. BCTs recommendations depend on the presence of physical and cognitive impairments, although 'goal setting', 'action planning', 'social support', 'problem solving' and 'restructuring of the social environment' are recommended in all people with first-ever stroke. The identified BCTs serve as the basis for further development of a personalized blended care intervention to reduce sedentary behavior in people with stroke.

Introduction

Over twenty-five percent of people with stroke experience a recurrent event within five years¹. Key risk factors for recurrent stroke are cardiovascular risk factors such as hypertension and impaired glucose tolerance^{2,3}. The reduction of the recurrence of stroke is in the top ten priorities for people with stroke⁴. Therefore, secondary prevention after a first-ever stroke is important. Sedentary behavior increases the risk of all-cause mortality and cardiovascular disease, including stroke⁵⁻⁹. Studies show that a reduction in the total amount of sedentary time reduces metabolic risk factors, like hypertension and impaired glucose tolerance, associated with an increased risk of cardiovascular diseases^{7,10,11}. Additionally, prolonged uninterrupted sedentary time, independent of total sedentary time, is associated with poor health and elevated cardiovascular risk factors^{7,11-15}. In people with stroke, a clinically relevant decrease of blood pressure was found by reducing and interrupting sedentary behavior¹⁶. Decreasing sedentary behavior could already produce health benefits in people with stroke^{6,10,14,17}.

Research has shown that people with stroke are even more sedentary compared to healthy peers, and sedentary time is accumulated in more prolonged sedentary bouts¹⁸⁻²¹. Since up to 40% of people with stroke experience a decline in activities of daily living after rehabilitation, it is important for patients to have self-management skills to preserve physical functioning²². In an elderly population, even small reductions in sedentary behavior increase physical functioning and decrease the prevalence of cardiovascular risk factors and mortality²³⁻²⁵. Additional to possible health benefits, a decrease of sedentary behavior could contribute to the prevention of the decline in physical functioning in people with stroke.

Only two intervention studies evaluated the effect of influencing sedentary time in a stroke population. The results of these studies are promising^{26,27}. The first study focused on increasing physical activity instead of reducing sedentary behavior, in addition, sedentary behavior was a secondary outcome measure²⁶. When targeting the reduction of sedentary behavior, the focus of an intervention should be primarily on reducing sedentary time and interrupting sedentary bouts^{6,23}. The second study was a feasibility study focussing on decreasing sedentary time and with a small sample²⁷. At this moment, a systematically developed intervention to reduce sedentary behavior in stroke survivors is lacking.

Before developing a behavior change intervention, well-defined intervention techniques for people with stroke need to be identified. The Behavior Change Wheel (BCW) is a step-by-step theory-based approach to develop behavior change interventions. The BCW is based on all behavior change frameworks and theories that currently exist^{28,29} (see figure I). The wheel has four layers. The first layer, the green part of the wheel, starts with Capability (physical

and psychological), Opportunity (social and physical), and Motivation (automatic and reflective) influencing behavior model (COM-B). These three factors enhance the likelihood of performing a specific behavior. The second layer, the yellow part, is the Theoretical Domains Framework, which supports the behavior model. The Theoretical Domains Framework consists 14 factors that are connected to a COM-B category (figure I). These 14 factors are physical skills; knowledge; cognitive and interpersonal skills; memory, attention and decision processes; behavioral regulation; environmental context and resources; social influences; professional/social role and identity; beliefs about capabilities; optimism; beliefs about consequences; intentions; goals; reinforcement; emotion. The third layer, the red part, contains nine intervention functions (Education, Persuasion, Incentivisation, Coercion, Training, Enablement, Modelling, Environmental Restructuring and Restrictions). Intervention functions are broad categories of means by which an intervention can change behavior. The intervention functions are linked to BCTs. The BCTs are the observable, replicable, irreducible, and active components of an intervention to change behavior²⁹. The fourth and final layer, the grey part, are the policy categories. These categories can be used to support the delivery of the intervention functions.

An intervention to reduce sedentary behavior in people with stroke should be personalized to improve outcomes³⁰. Additionally, personalization improves adherence and the uptake to the prescribed therapy³⁰. Therefore, this study aims to systematically determine the behavior change techniques (BCTs) for a behavioral change intervention directed at reducing sedentary behavior in community-dwelling, using the stages of the BCW.

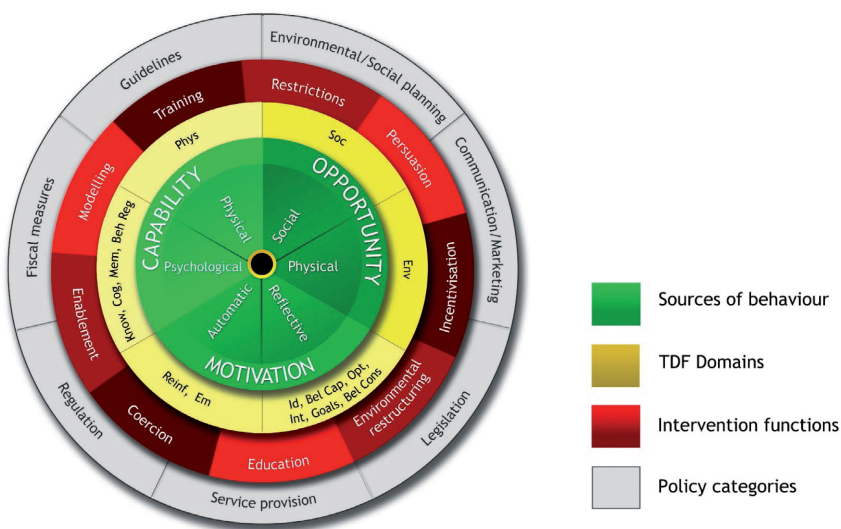


Figure I. The behavior change wheel and Theoretical Domains Framework. Reprinted with permission from Michie et al (Michie et al., 2011).

Abbreviations: Soc= social influences, env= environmental context and resources, id= social/professional role and identity, bel cap= beliefs about capabilities, opt= optimism, int= intentions, bel cons= beliefs about consequences, reinf= reinforcement, em= emotion, know= knowledge, cog= cognitive and interpersonal skills, mem= memory, attention and decision processes, beh reg= behavioral regulation, phys= physical skills

Methods

The step by step approach of the BCW was used to selected appropriate BCTs. The BCW involved a series of stages. These three stages are 1. Understanding the behavior; 2. Identify intervention functions; and 3. Identify BCTs and modes of delivery. Per stage, different methods were used to collect the information. Literature was searched until September 2018 within PubMed and Cinahl. Search strategies were formulated for Pubmed and adapted for use in Cinahl. Both the stages and the used methods are presented in figure II. Each stage is described in more detail below.

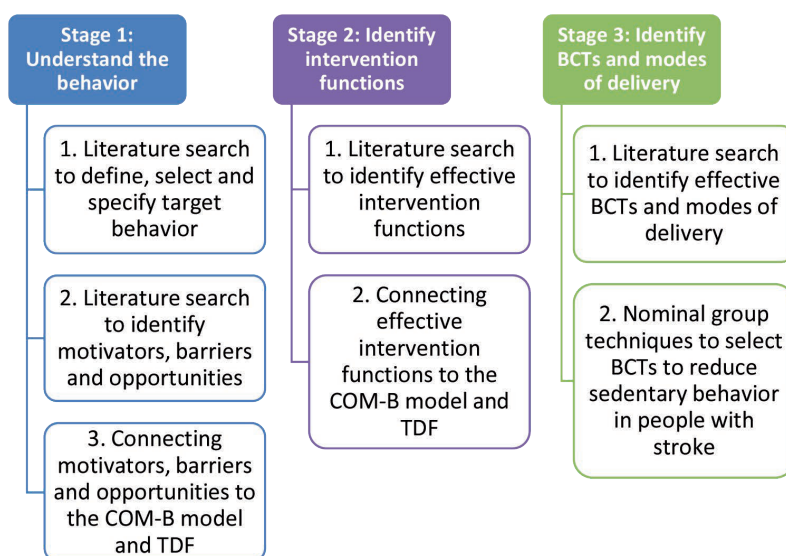


Figure II: Stages and used methods per stage.

Stage 1: Understanding the behavior

In stage 1, first, the target behavior was defined, selected, and specified using existing literature and by discussion in the research team. The research team consisted of six experts in the field of stroke, rehabilitation, physiotherapy, movement behavior, and/or behavioral change. Second, a literature search was conducted to get insight into the behavioral diagnosis. The researchers WH and RW conducted a literature study to identify motivators, barriers, and opportunities regarding sedentary behavior in people with stroke (see table I for search terms). Literature was searched until no new motivators, barriers, and opportunities were found. The motivators, barriers, and opportunities were connected to the COM-B model and the Theoretical Domains Framework (figure I) by WH and RW. The results were discussed in the research team, and adjustments were made where needed.

Table I. Search terms related to the step of the Behavior Change Wheel.

Questions per stage		Search terms
Stages 1 Understand the behavior	What should be the target behavior?	Sedentary behavior* AND stroke OR risk
	What motivations, barriers and opportunities are identified with regards to reducing sedentary behavior?	'Sedentary behavior*' AND 'Barrier*' OR 'Motivation'
Stage 2 Identify intervention functions	What is the evidence on the effectiveness of the possible intervention functions in stroke survivors with regards to reducing sedentary behavior?	'Behavioral interventions' OR 'lifestyle intervention' OR 'Selfmanagement' OR 'Education' AND 'Sedentary Behavior' AND 'Stroke' [#] 'Behavioral interventions' OR 'lifestyle intervention' OR 'Selfmanagement' OR
Stage 3 Identify behavior changes techniques and modes of delivery	What is the evidence on the effectiveness of the possible BCTs in stroke survivors with regards to reducing sedentary behavior?	'Education' AND 'Sedentary Behavior' 'Stroke' [#] AND 'Behavioral interventions' OR 'lifestyle intervention' OR
	What is the evidence on the effectiveness of the possible modes of delivery in stroke survivors with regards to reducing sedentary behavior?	'Selfmanagement' OR 'Education' OR 'Secondary Prevention' OR 'Risk Reduction Behavior' OR 'Lifestyle modification'

[#]'Stroke' OR 'Brain Infarction' OR 'Cerebro Vascular Accident' OR 'CVA' OR 'Cerebral apoplexy' OR 'Poststroke*'

Stage 2: Identify intervention functions

To identify effective intervention functions, a literature search was conducted. Effective intervention functions were retrieved out of literature by WH and RW. Search terms used are presented in table I. The identified effective intervention functions were connected to the COM-B model and Theoretical Domains Framework by WH and RW. The research team reflected on this and, if needed, adjustments were carried out.

Stage 3: Identify behavior change techniques and modes of delivery

First, effective BCTs and the modes of delivery were identified from the literature. Second, Nominal Group Technique (NGT) sessions with professionals working with people with stroke and researchers were undertaken.

Literature research

Effective BCTs and modes of delivery were retrieved from the literature by WH and RW. Search terms used are presented in table I. An overview of BCTs that were found to be effective, not effective, conflicting evidence or no evidence to reduce sedentary behavior was made. WH and RW independently recoded the BCTs of the retrieved intervention

studies to the BCW method if needed. In case of disagreement, a third researcher (MP) was consulted. Effective modes of delivery were listed.

Nominal Groups Techniques

After the literature study, Nominal Groups Technique sessions were performed and facilitated by WH and RW. The Nominal Group Technique sessions were undertaken because it was expected that the retrieved BCTs were mainly based on a healthy population. Instead, interventions should be tailored to people with stroke, and therefore other BCTs could be more suitable to the stroke population. Additionally, symptoms after stroke are diverse, and personalization of interventions is needed to improve the uptake of an intervention^{30,31}. Therefore, four profiles of people with stroke were formulated by the research team based on literature³¹ and best practice experience: profile 1. no physical or cognitive impairments; profile 2. mainly cognitive impairments; profile 3. mainly physical impairments; and profile 4. both physical and cognitive impairments.

Two groups were impaneled formulated to carry out the Nominal Group Technique sessions. Group one, professionals, consisted of physiotherapists working with people with stroke in a hospital, rehabilitation center, and in private practice. All professionals were working in the stroke service of Utrecht. Group two, researchers, were working in the field of behavioral change, people with stroke, and movement behavior. International researchers were asked by email to participate in this study. Since the researchers reside in different parts of the world, it was decided to use individual interviews within the NGT structure to receive their input on the content of the intervention. Both the group sessions and interviews were audio-recorded.

Both professionals and experts received an overview of the BCTs found in the literature to be effective, not effective, generating conflicting evidence or no evidence before the interview or NGT face-to-face session. The professionals and researchers were asked to identify all BCTs that might be relevant for the intervention. Based on the answers, the possible relevant BCTs were provided to all participants. The participants and researchers were asked to individually choose the eight most important BCTs per profile to reduce sedentary behavior in people with stroke³². Each individual made their choice by rating the BCTs; eight points were given to the BCT deemed most important, seven points to the second most important BCT and so on. The scores of the individuals were summed per stroke profile, resulting in an overview of the most important BCTs to reduce sedentary behavior per profile.

Results

Stage 1: Understanding the behavior

Based on existing literature and discussion within the research group, two target behavior were selected. The first target behavior is to reduce total time spent sedentary^{5-12,14,33}. The BUST-study found a statistically and clinically relevant decrease of the systolic blood pressure by interrupting sedentary behavior every thirty minutes with a walk of three minutes¹⁶. Therefore, the second target behavior is to reduce time spent in sedentary behavior accumulated in bouts over thirty minutes.

From the literature study searching motivations, barriers, and opportunities to reduce sedentary behavior in people with stroke, one study, including people after stroke, was found³⁴. The study found that there is limited awareness of the health risks of sedentary behavior among people with stroke. The main reasons for sedentary behavior were relaxation, comfort, sedentary occupation, or inability to get back to work. It was concluded that participants encountered barriers in their daily lives that affect engagement in activities. The main barriers are motor impairments, fatigue, cognitive problems, depression, lack of support from friends and family and lack of motivation to be physically active. Strategies involving wearable technologies for self-monitoring, movement throughout the day, and action planning to reduce sedentary behavior were found as potential ways to reduce sedentary behavior according to people with stroke. An additional search focussing on an elderly population resulted in one study, including elderly women³⁵. This resulted in fifteen reasons to sit, fourteen motivators, and six opportunities. All motivators, barriers, and opportunities were connected to the COM-B model and Theoretical Domains Framework and can be found in Table II.

Stage 2: Identify intervention functions

No evidence was found on intervention functions specific to reduce sedentary behavior in people with stroke. Three systematic reviews were found on reducing sedentary behavior in general populations³⁶⁻³⁸. The following intervention functions were found to be effective and connected to the TDF domains (see table II): persuasion, incentivization (based on one study), training, environmental restructuring, and restriction.

Table II. Capabilities, opportunities, motivation and behavioral diagnosis, the results of step 4 of the Behavior Change Wheel.

COM-B	COM-B Components	TDF	What needs to happen for people with stroke to reduce sedentary behavior?	Motivators/barriers	Intervention function
Capability	Physical capability	Physical skills	Being capable of replacing sitting with LPA	Overcome motor impairments, therapeutic exercise, short activities, moving throughout the day	Training
	Psychological capability	Knowledge	Having sufficient knowledge on the health consequences of sedentary time and sedentary bouts; Having sufficient knowledge of own sedentary behavior; Having sufficient knowledge about how to reduce sedentary time and interrupt sedentary bouts. Having the skills to decrease sedentary time; Having the skills to develop specific plans to interrupt sedentary bouts and reduce sedentary time	Awareness of health risks of sedentary behavior	Education
Opportunity	Physical opportunity	Cognitive and interpersonal skills	Remember to decrease sedentary time and interrupt sedentary bouts;	Self-motivation and determination, action planning, self-monitoring	Training
		Memory, attention and decision processes	Behavioral regulation	Cognitive problems	Training, environmental restructuring
	Social opportunity	Environmental context and resources	Break sitting habits; Self-monitoring to observer sedentary behavior	Relaxation, comfort, sitting is a habit, sitting is a reward	Education, training
		Social influences	Access to activities that are not in the sitting position; Having the opportunity to interrupt sedentary behavior during work or at home; Having the in-house and outside environmental factors	All activities are in sitting position, nothing to do, sedentary occupation or unable to get back to work, in-house environmental factors, outside environmental factors, safe environment, go to community-based activities, fear of walking outside because not enough places to rest, fear of embarrassment if could not manage without rest, movement to the day	Training, environmental restructuring, restriction
		Relatives need to have sufficient knowledge about sedentary time and interrupting sedentary bouts; Encourage, stimulate decrease of sedentary time and interrupt sedentary bouts from friends and family;	Lack of support from friends and family, the pressure of family and friends to rest, sit because do not want to burden others, feeling useful, social support, socializing, relieve boredom, not just be the old person in the chair	Environmental restructuring,	

Table II. (Continued)

COM-B	COM-B Components	TDF	What needs to happen for people with stroke to reduce sedentary behavior?	Motivators/barriers	Intervention function
Motivation	Reflective motivation	Professional/social role and identity Beliefs about capabilities	Decrease sedentary time and interrupt sedentary bouts at the workplace Overcome fatigue, depression, cognitive problems, pain, poor sleep. (self)-monitoring of behavior to have insight about the sedentary time and sedentary bouts; Have self-motivation and determination; Cope with fear of walking outdoors, fear of embarrassment, fear of falling Motivated to change sedentary behavior; Belief in the positive effect on the risk of recurrent stroke, pain, depression, feeling less guilty, feeling independent, relieve boredom, poor sleep Have the personal motivation to reduce sedentary time and interrupt sedentary bouts	Sedentary occupation Fatigue, depression, cognitive problems, pain, poor sleep, lack of motivation, feel capable of self-caring, self-motivation, and determination Fear of walking outside, fear of embarrassment, fear of falling, feel capable of self-caring, feeling less guilty, feeling independent Pain, depression, feeling less guilty, feeling independent, relieve boredom, poor sleep, coping mechanics to relieve depression Personal motivation	Education, (persuasion) Education, persuasion, training
		Optimism			Education, persuasion
		Beliefs about consequences			Education, persuasion
		Intentions			Education, persuasion, incentivization
		Goals	Action planning, Being active during the day;	Action planning, being active during the day,	Education, persuasion, incentivization
Automatic motivation		Reinforcement	Establish routines to interrupt sedentary bouts; Create other habits instead of sitting;	Sitting is a habit, nothing to do	Training, environmental restructuring Incentivization
		Emotion	Experience a positive emotional response decreasing sedentary time and interrupt sedentary bouts	Fatigue, depression, fear of walking, fear of embarrassment, fear of falling, feeling independent, feeling useful, feeling less guilty	

Com-B=Capabilities, opportunities, motivation and behavioral diagnosis, TDF=Theoretical Domains Framework, LPA=Light Physical Activity

Stage 3: Identify behavior change techniques and modes of delivery

Literature study

No evidence on BCTs and modes of delivery specific to reduce sedentary behavior was found for people with stroke. Three systematic reviews were found on reducing sedentary behavior in general populations^{36–38}. The overall conclusion of the reviews was that lifestyle interventions targeting sedentary behavior individually or targeting sedentary behavior and physical activity at the same time are effective^{36–38} for reducing sedentary time. One review coded the content of the included interventions to BCT³⁷. For the other two reviews, the authors RW and WH coded the content of the included interventions to BCTs^{36,38}. An overview of BCTs that were found to be useful is provided in the additional file I, table I. The identified modes of delivery were face to face group, web-based personal, written materials, and activity monitors.

Nominal Group Techniques sessions

In total, six professionals and five researchers participated in the Nominal Group Techniques sessions. The average age of the professionals was 36 years (range 23 to 51). The average work experience was 13 years (range 2 to 30). All had a bachelor's degree in physiotherapy, and two had an additional master's degree in physiotherapy sciences. Two currently worked in an academic hospital, two worked in a rehabilitation center and two worked in private practice. All of the professionals were working with people with stroke on a regular basis. The average age of the researchers was 44 (range 41 to 49). All but one had a background as a physiotherapist; the other one was a neuropsychologist. All researchers had a Ph.D. and worked at least part-time as a researcher. All had movement behavior and/or stroke as their area of expertise.

The participants identified, in total, 75 BCTs as possibly eligible to include in an intervention to reduce sedentary behavior. A mean of 30 BCTs per profile received points (range 29–33 BCTs). Overall 'goal-setting', 'action planning', 'social support', 'problem solving' and 'restructuring the social environment' were selected in all four profiles. 'Self-monitoring', 'feedback on behavior', 'information about health consequences' and 'goal setting on outcome' were selected for both profiles without cognitive impairments, and 'prompts/cues', 'graded tasks', 'restructuring the physical environment' and 'social support practical' were selected for both profiles with cognitive impairments. An overview of the ten most eligible BCTs per profile can be found in Table III. An overview of the ranking and frequency of the BCTs for the four different profiles can be found in Additional file I, table II - V .

Table III: Final ranking BCTs per profile

	Patients without physical nor cognitive impairments	Patients with cognitive impairments and without physical impairments	Patients with physical impairments and without cognitive impairments	Patient with both physical and cognitive impairments
1.	Goal setting (behavior)	Goal setting (behavior)	Goal setting (behavior)	Goal setting (behavior)
2.	Action planning	Action planning	Problem solving	Social support (unspecified)
3.	Social support (unspecified)	Social support (unspecified)	Action planning	Prompts/cues
4.	Self-monitoring (behavior)	Prompts/cues	Social support (unspecified)	Problem solving
5.	Goal setting (outcome)	Restructuring the physical environment	Self-monitoring (behavior)	Restructuring the social environment
6.	Feedback on behavior	Problem solving	Restructuring the physical environment	Restructuring the physical environment
7.	Discrepancy between current behavior and goal	Social support (practical)	Restructuring the social environment	Action planning
8.	Information about health consequences	Restructuring the social environment	Goal setting (outcome)	Social support (practical)
9.	Problem solving	Graded tasks	Feedback on behavior	Graded tasks
10.	Restructuring the social environment	Social reward & feedback on behavior	Information about health consequences	Social reward & review behavior goal(s)

Discussion

The aim of this study was to determine BCTs for a behavioral change intervention to reduce sedentary behavior in people with stroke using the BCW. BCTs were ranked by professionals and researchers after the literature was reviewed and the main elements were extracted. In summary, 'goal-setting', 'action planning', 'social support', 'problem solving', and 'restructuring the social environment' were found to be main elements to be included in an intervention to reduce sedentary behavior in all people with stroke.

Target behavior

Reducing sedentary behavior needs to be the target behavior and the focus within an intervention, rather than enhancing physical activity³⁷. Sedentary behavior and reaching sufficient levels of physical activity are two different behavioral constructs³⁹. Additionally, it is difficult for people with stroke to achieve adequate levels of moderate to vigorous physical activity⁴⁰. Focussing entirely on sedentary behavior can already contribute to secondary prevention and could be more achievable for people with stroke, including those with ambulatory difficulties. However, a part of the population could be able to reach sufficient amounts of physical activity. In this subpopulation, sedentary interventions should be implemented alongside physical activity and exercise interventions to reach an optimal reduction of cardiovascular risk factors³⁹.

It remains unclear how much reduction is needed in total sedentary time and in breaking up prolonged bouts of sedentary behavior to gain health benefits. Already, small improvements seem to have health benefits in other populations^{9,13,14}.

Motivators, Barriers, and Opportunities

Only one study is conducted investigating the barriers and motivators to reduce sedentary behavior in people with stroke. This study provided important information with regards to the capabilities, opportunities, and motivators in people with stroke to remain sedentary³⁴. However, for further development of the intervention content, it will be important to include people with stroke and their carers to be sure the content connects to the target population^{41,42}.

Behavior Change Techniques

The identification of BCTs was accomplished through the comprehensive use of the BCW. The BCW ensures that there is a clear definition of the behavior and the change needed; this is to make sure there is a thorough understanding of all the aspects of the behavior.

At least seven BCTs should be included in an intervention. In a review on reducing sedentary behavior in a general population, it was found that effective interventions included at least seven BCTs³⁷. Little is known about the number of BCTs. Therefore, we presented the top ten BCTs per profile. However, more research is needed to include a sufficient amount of BCTs in an intervention.

Personalization of care is important, especially in the stroke population where complaints after stroke are diverse³⁰. Although self-monitoring seems to be one of the essential BCTs to reduce sedentary behavior, this could be difficult to implement, interpret, and translate into behavior change in people with stroke with cognitive problems⁴³. A different approach for these patients could be more effective. The results of our study show that social support needs to be included in the intervention for people with stroke with cognitive impairments. The involvement and support of family and friends are therefore highly recommended. Additionally, 68% of people with stroke have at least one cognitive complaint⁴⁴, and the variety of physical limitations is wide⁴⁵. This underlines the importance of tailoring the intervention³⁰. When the individual needs, limitations, and motivators of people with stroke are taken into account, adherence to the intervention will increase³⁰. The profiles used in our study can guide the selection of BCTs and the personalization of the intervention.

In this study, the most essential BCTs to reduce sedentary behavior in people with stroke were identified. Further research should focus on the effectiveness of the BCTs for both target behaviors, i.e., sedentary behavior, in people with stroke. In such research, it is essential to describe BCTs using the Behavior Change Technique Taxonomy²⁹. Thorough intervention descriptions in protocol articles are needed, and intervention protocols should be available to use in practice. Description of included BCTs, the frequency of use, the intensity, and the way BCTs are delivered is crucial. In addition, education on how to implement and execute BCTs in daily practice is important too. For example, goal-setting is one of the most critical BCTs recommended in stroke rehabilitation⁴⁶. However, the determination of goal-setting seems to be difficult, and health care professionals find it difficult to make goals that are patient-centered^{47–49}. Education to overcome these problems could be explored and implemented to improve the quality of goal-setting.

Modes of delivery

The identified modes of delivery were face to face contact, group delivery, web-based personal, written materials standard, and activity monitors. The results of our study underline the importance of a blended care intervention. To optimize personalized secondary prevention, blending care seems to be promising. The use of a computer, mobile, and a wearable device (eCoaching) can be effective in reducing sedentary behavior⁵⁰. Persuasive eCoaching, the use of technology during coaching to motivate and stimulate people to

change attitudes, behavior, and rituals⁴¹, could be useful in reducing sedentary behavior in people with stroke, but this needs further research. ECoaching on its own showed only short term effects⁵⁰. Whereas eCoaching and face-to-face contacts together showed more sustainable behavioral changes⁵¹. However, this is not yet investigated in people with stroke. Activity monitors are highly important to gain insight into individual behavior and give real-time feedback on behavior³⁷. Therefore, an intervention, including activity trackers, persuasive eCoaching, and face-to-face contact, could be a promising approach⁴¹. Although the most important modes of delivery and BCTs are identified, a detailed description of an intervention needs to be further explored.

Study limitations

Based on the amount of consistent literature found and the thoroughness of the search, the literature research seems complete and comprehensive, although this is not a systematic review. Some information was retrieved out of other populations and should be further investigated in a population with people with stroke. Another limitation is that even though the description of the BCTs is quite elaborate, there is still some room for interpretation. Care was taken to make comprehension of the BCTs as clear as possible.

To get the insights of the researchers, the original Nominal Group Techniques process could not be followed. To make sure the most renowned researchers were involved in the selection of the BCTs, it was decided to include not just Dutch experts but researchers from around the world. Therefore, the NGT method was converted into an interview-based method. Although some of the group dynamics were compromised, a step-based method was used to ensure that all participants were informed of the identified possible BCTs before the individual ranking.

Almost all participants stated that their choice of the use of a BCT in clinical practice is partially based on the person in front of them and their limitations caused by the stroke. This is in line with the distinction made in the ranking by using the four profiles; these profiles are an attempt, at this point in the development, to do as much justice as possible to the individual differences. However, personal factors have to be taken into account. Additional to stroke characteristics, personal factors like coping style, neuroticism, and optimism are associated with functioning after stroke⁵². When personalize an intervention these factors should be taken in to account. This study provides important information to personalize an intervention by selecting the right BCTS and mode of delivery based on the individual. Within the development of an intervention all stakeholders should be included. Within the design team for behavioral change interventions in stroke patients, all professionals involved in stroke care, people with stroke themselves, proxies, behavioral

experts, and as well as technology experts should be included from the start of the design process⁴².

Conclusion

Behavior change techniques were identified for a behavioral change intervention aiming to reduce sedentary behavior in community-dwelling people with first-ever stroke. BCTs recommendations depend on the presence of physical and cognitive impairments, although 'goal setting', 'action planning', 'social support', 'problem solving' and 'restructuring of the social environment' is recommended in all people with first-ever stroke. The identified BCTs serve as the basis for further development of a personalized blended care intervention to reduce sedentary behavior in people with stroke.

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Appendix

Table I. Intervention functions, BCT's and modus of delivery found effective in general population based on literature

Intervention functions	BCT	Modus of delivery
Education	Problem solving	Face to face group
Persuasion	Goal setting (outcome)*	Web-based personal*
Incentivisation*	Action planning	Written materials standard
Training	Commitment*	Pedo- / accelerometer not specified
Environmental restructuring	Monitoring behavior by others without feedback*	
Restriction	Feedback on Behavior	
	Self-monitoring (behavior)	
	Instruction on how to preform behaviors	
	Information about health consequences	
	Demonstration of the behavior	
	Remove access to the reward	
	Behavioral practice/rehearsal	
	Habit reversal*	
	Overcorrection*	
	Generalisation of target behavior*	
	Graded tasks	
	Credible source*	
	Pros and cons*	
	Material reward for behavior	
	Adding objects to the environment	

*Based on one study

Table II. Profile 1 no physical impairment and no cognitive impairment

Ranking	Professionals			Researchers			Total		
	BCtNr	Name	Points	BCtNr	Name	Points	BCtNr	Name	Points
1	1.1	Goal setting (behavior)	39	1.4	Action planning	19	1.1	Goal setting (behavior)	54
2	1.4	Action planning	33	1.2	Problem solving	17	1.4	Action planning	52
3	3.1	Social support (unspecified)	23	1.3	Goal setting (outcome)	16	3.1	Social support (unspecified)	35
4	5.1	Information about health consequences	14	1.1	Goal setting (behavior)	15	2.3	Self-monitoring (behavior)	24
5	2.2	Feedback on Behavior	14	2.3	Self-monitoring (behavior)	15	1.3	Goal setting (outcome)	23
6	8.4	Habit reversal	11	1.6	Discrepancy between current behavior and goal	12	2.2	Feedback on Behavior	21
7	2.3	Self-monitoring (behavior)	9	3.1	Social support (unspecified)	12	1.6	Discrepancy between current behavior and goal	20
8	1.6	Discrepancy between current behavior and goal	8	12.1	Restructuring the physical environment	11	5.1	Information about health consequences	20
9	12.2	Restructuring the social environment	8	2.2	Feedback on Behavior	7	1.2	Problem solving	17
10	15.3	Focus on past success	8	12.2	Restructuring the social environment	7	12.2	Restructuring the social environment	15
11	13.3	Incompatible beliefs	7	1.5	Review behavior goal(s)	6	8.4	Habit reversal	11
12	1.3	Goal setting (outcome)	7	5.1	Information about health consequences	6	1.5	Review behavior goal(s)	11
13	7.1	Prompts/cues	6	12.3	Avoidance/reducing exposure to cues for the behavior	6	12.1	Restructuring the physical environment	11
14	8.7	Graded tasks	5	8.7	Graded tasks	5	8.7	Graded tasks	10
15	3.2	Social support (practical)	5	2.4	Self-monitoring of outcome(s) of behavior	5	15.3	Focus on past success	9
16	1.5	Review behavior goal(s)	5	8.1	Behavioral practice/rehearsal	4	7.1	Prompts/cues	9
17	10.4	Social reward	4	10.4	Social reward	4	10.4	Social reward	8
18	12.6	Body changes	4	7.1	Prompts/cues	3	13.3	Incompatible beliefs	7

Table II. (Continued)

Ranking	Professionals		Researchers		Total		Points	Frequency professionals / researchers		
	BCTnr	Name	Points	BCTnr	Name	Points				
19	9.1	Credible source	3	10.5	Social incentive	3	12.3	Avoidance/reducing exposure to cues for the behavior	6	2/1=3
20	15.1	Verbal persuasion about capability	2	5.4	Monitoring of emotional consequences	2	2.4	Self-monitoring of outcome(s) of behavior	5	0/2=2
21	11.2	Reduce negative emotions	1	8.3	Habit formation	2	3.2	Social support (practical)	5	1/0=1
22				10.3	Non-specific reward	2	8.1	Behavioral practice/ rehearsal	4	0/1=1
23				15.3	Focus on past success	1	12.6	Body changes	4	2/0=2
24							9.1	Credible source	3	1/0=1
25							10.5	Social incentive	3	1/0=1
26							5.4	Monitoring of emotional consequences	2	1/0=1
27							10.3	Non-specific reward	2	0/2=2
28							15.1	Verbal persuasion about capability	2	1/0=1
29							8.3	Habit formation	2	0/1=1
30							11.2	Reduce negative emotions	1	1/0=1

Table III. Profile 2 no physical impairment, cognitive impairment

Ranking	Professionals		Researchers		Total					
	BCTNr	Name	Points	BCTNr	Name	Points	BCTNr	Name	Points	Frequency professionals /researchers
1	1.1	Goal setting (behavior)	46	1.1	Goal setting (behavior)	21	1.1	Goal setting (behavior)	67	6/3=9
2	1.4	Action planning	32	3.1	Social support (unspecified)	20	1.4	Action planning	38	5/1=6
3	7.1	Prompts/cues	28	12.1	Restructuring the physical environment	13	3.1	Social support (unspecified)	38	3/3=6
4	3.1	Social support (unspecified)	18	8.7	Graded tasks	11	7.1	Prompts/cues	38	5/4=9
5	1.2	Problem solving	15	7.1	Prompts/cues	10	12.1	Restructuring the physical environment	26	3/3=6
6	12.1	Restructuring the physical environment	13	3.2	Social support (practical)	10	1.2	Problem solving	22	2/1=3
7	12.5	Adding objects to the environment	10	2.2	Feedback on Behavior	9	3.2	Social support (practical)	19	2/2=4
8	3.2	Social support (practical)	9	14.4	Reward approximation	9	12.2	Restructuring the social environment	14	2/1=3
9	12.2	Restructuring the social environment	7	1.3	Goal setting (outcome)	8	8.7	Graded tasks	12	1/2=3
10	3.3	Social support (emotional)	5	1.2	Problem solving	7	10.4	Social reward	11	1/2=3
11	8.3	Habit formation	5	1.6	Discrepancy between current behavior and goal	7	2.2	Feedback on Behavior	11	1/2=3
12	8.6	Generalisation of target behavior	4	10.3	Non-specific reward	7	1.5	Review behavior goal(s)	10	1/1=2
13	10.4	Social reward	4	10.4	Social reward	7	12.5	Adding objects to the environment	10	3/0=3
14	12.6	Body changes	4	12.2	Restructuring the social environment	7	14.4	Reward approximation	9	0/2=2
15	1.5	Review behavior goal(s)	4	1.4	Action planning	6	1.3	Goal setting (outcome)	8	0/1=1
16	9.1	Credible source	3	1.5	Review behavior goal(s)	6	10.3	Non-specific reward	8	1/2=3
17	2.2	Feedback on Behavior	2	12.3	Avoidance/reducing exposure to cues for the behavior	6	1.6	Discrepancy between current behavior and goal	7	0/1=1



Table III. (Continued)

Ranking	Professionals			Researchers			Total		
	BCTnr	Name	Points	BCTnr	Name	Points	BCTnr	Name	Points
18	15.1	Verbal persuasion about capability	2	5.1	Information about health consequences	5	8.3	Habit formation	6
19	5.1	Information about health consequences	1	10.5	Social incentive	3	5.1	Information about health consequences	6
20	8.7	Graded tasks	1	7.4	Remove access to the reward	2	12.3	Avoidance/reducing exposure to cues for the behavior	6
21	9.2	Pros and cons	1	8.2	Behavior substitution	2	3.3	Social support (emotional)	5
22	10.3	Non-specific reward	1	5.4	Monitoring of emotional consequences	1	8.6	Generalisation of target behavior	4
23	11.2	Reduce negative emotions	1	7.8	Associative learning	1	12.6	Body changes	4
24				8.1	Behavioral practice/ rehearsal	1	9.1	Credible source	3
25				8.3	Habit formation	1	10.5	Social incentive	3
26							7.4	Remove access to the reward	2
27							15.1	Verbal persuasion about capability	2
28							8.2	Behavior substitution	2
29							8.1	Behavioral practice/ rehearsal	1
30							5.4	Monitoring of emotional consequences	1
31							7.8	Associative learning	1
32							11.2	Reduce negative emotions	1
33							9.2	Pros and cons	1

Table IV. Profile 3 physical impairment, no cognitive impairment

Ranking	Professionals		Researchers		Total					
	BCTNr	Name	Points	BCTNr	Name	Points	BCTNr	Name	Points	Frequency professionals /researchers
1	1.1	Goal setting (behavior)	38	1.4	Action planning	19	1.1	Goal setting (behavior)	53	5/2=7
2	1.2	Problem solving	29	12.1	Restructuring the physical environment	18	1.2	Problem solving	46	4/3=7
3	1.4	Action planning	26	1.2	Problem solving	17	1.4	Action planning	45	4/3=7
4	3.1	Social support (unspecified)	19	1.3	Goal setting (outcome)	16	3.1	Social support (unspecified)	30	3/3=6
5	2.3	Self-monitoring (behavior)	14	1.1	Goal setting (behavior)	15	2.3	Self-monitoring (behavior)	29	3/3=6
6	12.2	Restructuring the social environment	10	2.3	Self-monitoring (behavior)	15	12.1	Restructuring the physical environment	24	1/3=4
7	15.3	Focus on past success	10	3.1	Social support (unspecified)	11	12.2	Restructuring the social environment	19	3/2=5
8	7.1	Prompts/cues	8	12.2	Restructuring the social environment	9	1.3	Goal setting (outcome)	16	0/2=2
9	12.6	Body changes	8	1.6	Discrepancy between current behavior and goal	7	2.2	Feedback on Behavior	12	1/2=3
10	5.1	Information about health consequences	7	2.2	Feedback on Behavior	7	5.1	Information about health consequences	12	3/1=4
11	12.1	Restructuring the physical environment	6	1.5	Review behavior goal(s)	6	7.1	Prompts/cues	11	2/1=3
12	8.4	Habit reversal	5	12.3	Avoidance/reducing exposure to cues for the behavior	6	3.2	Social support (practical)	10	1/1=2
13	2.2	Feedback on Behavior	5	3.2	Social support (practical)	5	15.3	Focus on past success	10	4/0=4
14	2.7	Feedback on outcome(s) of behavior	5	5.1	Information about health consequences	5	10.4	Social reward	8	1/1=2
15	3.2	Social support (practical)	5	8.7	Graded tasks	4	12.6	Body changes	8	3/0=3
16	8.1	Behavioral practice/rehearsal	4	10.4	Social reward	4	1.6	Discrepancy between current behavior and goal	7	0/2=3
17	9.2	Pros and cons	4	2.4	Self-monitoring of outcome(s) of behavior	4	1.5	Review behavior goal(s)	6	0/1=1



Table IV. (Continued)

Ranking	Professionals			Researchers			Total			
	BCTnr	Name	Points	BCTnr	Name	Points	BCTnr	Name	Points	Frequency professionals /researchers
18	10.4	Social reward	4	7.4	Remove access to the reward	3	12.3	Avoidance/reducing exposure to cues for the behavior	6	0/1=1
19	9.1	Credible source	3	10.5	Social incentive	3	2.7	Feedback on outcome(s) of behavior	5	1/0=1
20	15.1	Verbal persuasion about capability	2	8.3	Habit formation	2	8.1	Behavioral practice/rehearsal	5	1/1=2
21	5.4	Monitoring of emotional consequences	2	10.3	Non-specific reward	2	8.4	Habit reversal	5	2/0=2
22	11.2	Reduce negative emotions	1	5.4	Monitoring of emotional consequences	1	2.4	Self-monitoring of outcome(s) of behavior	4	0/2=2
23	12.5	Adding objects to the environment	1	8.1	Behavioral practice/ rehearsal	1	9.2	Pros and cons	4	1/0=1
24							9.1	Credible source	3	1/0=1
25							5.4	Monitoring of emotional consequences	3	1/1=2
26							10.5	Social incentive	3	0/1=1
27							10.3	Non-specific reward	2	0/2=2
28							15.1	Verbal persuasion about capability	2	1/0=1
29							8.3	Habit formation	2	0/1=1
30							11.2	Reduce negative emotions	1	1/0=1
31							12.5	Adding objects to the environment	1	1/0=1

Table V. Profile 4 physical impairment, cognitive impairment

Ranking	Professionals			Researchers			Total		
	BCTNr	Name	Points	BCTNr	Name	Points	BCTNr	Name	Points
1	1.1	Goal setting (behavior)	44	1.1	Goal setting (behavior)	21	1.1	Goal setting (behavior)	65
2	3.1	Social support (unspecified)	32	3.1	Social support (unspecified)	20	3.1	Social support (unspecified)	52
3	7.1	Prompts/cues	28	12.1	Restructuring the physical environment	14	7.1	Prompts/cues	38
4	1.2	Problem solving	27	8.7	Graded tasks	11	1.2	Problem solving	35
5	1.4	Action planning	14	7.1	Prompts/cues	10	12.2	Restructuring the social environment	21
6	12.2	Restructuring the social environment	11	12.2	Restructuring the social environment	10	12.1	Restructuring the physical environment	21
7	3.2	Social support (practical)	9	2.2	Feedback on Behavior	9	1.4	Action planning	20
8	12.5	Adding objects to the environment	9	3.2	Social support (practical)	9	3.2	Social support (practical)	18
9	12.1	Restructuring the physical environment	7	14.4	Reward approximation	9	8.7	Graded tasks	12
10	8.3	Habit formation	6	1.3	Goal setting (outcome)	8	10.4	Social reward	11
11	12.6	Body changes	5	1.2	Problem solving	7	1.5	Review behavior goal(s)	11
12	1.5	Review behavior goal(s)	5	6.1	Demonstration of the behavior	7	12.5	Adding objects to the environment	9
13	8.4	Habit reversal	4	10.3	Non-specific reward	7	2.2	Feedback on Behavior	9
14	10.4	Social reward	4	10.4	Social reward	7	14.4	Reward approximation	9
15	10.3	Non-specific reward	2	1.4	Action planning	6	10.3	Non-specific reward	9
16	15.1	Verbal persuasion about capability	2	1.5	Review behavior goal(s)	6	1.3	Goal setting (outcome)	8
17	8.7	Graded tasks	1	12.3	Avoidance/reducing exposure to cues for the behavior	6	8.3	Habit formation	7
18	11.2	Reduce negative emotions	1	5.1	Information about health consequences	4	6.1	Demonstration of the behavior	7

Table V. (Continued)

Ranking	Professionals		Researchers		Total		Points	Frequency professionals / researchers
	BCTnr	Name	BCTnr	Name	BCTnr	Name		
19	13.3	Incompatible beliefs	1		10.5	Social incentive	3	0/1=1
20					8.2	Behavior substitution	2	3/0=3
21					5.4	Monitoring of emotional consequences	1	1/0=1
22					7.4	Remove access to the reward	1	0/1=1
23					7.8	Associative learning	1	0/1=1
24					8.3	Habit formation	1	1/0=1
25								
26								
27								
28								
29								
30								



CHAPTER 9



GENERAL DISCUSSION

Recovery after stroke is a complex process. Due to advances in the acute medical treatment of stroke, a growing number of people live with the consequences, therefore, stroke can be seen as a chronic condition. The majority of the stroke population has minor symptoms and is discharged from the hospital with or without primary care. Also, people after first-stroke are at high risk of having a recurrent cardiovascular event. More attention could be paid to long term follow-up care and secondary prevention because premature death, and disability rates are higher after recurrent stroke than after the first stroke. One of the critical risk factors to address in prevention is movement behavior. The general aim of this thesis was to identify unfavorable movement behavior pattern(s) in people with stroke and the consequences of this movement behavior with regard to their physical functioning during the first year after stroke. The results of the studies were presented in the previous chapters and based on the RISE (Reducing sedentary behavior, Identification of people at risk, in people with Stroke, Effectiveness in daily living) cohort study (figure I), performed between 2015 and 2019. In this general discussion section, the main findings are discussed, methodological considerations are provided, and clinical and educational implications and suggestions for future stroke research will be presented.



Figure I. RISE-study

Main findings and discussion

National and international recommendations regarding moderate-to-vigorous physical activity (MVPA) and ‘move more, sit less’ are the same for healthy adults as for adults with chronic health conditions, including people with stroke. The results of chapters 5 and 6 show that almost all people with stroke can optimize their movement behavior. Within the average 13.7 hours accelerometer wearing time people were on average 9.3 hours sedentary, showed 3.8 hours light physical activity (LPA), 0.6 MVPA, 0.2 MVPA accumulated in bouts ≥ 10 minutes and 4.0 hours sedentary accumulated in bouts ≥ 30 minutes. Therefore it is concluded that the majority of the population with stroke is highly sedentary, and a substantial proportion was found to be inactive.

Recently, a large meta-analysis of Ekelund et al., including over 36.000 adults, was conducted to investigate the dose-response association of movement behavior outcomes and all-cause mortality. In that study, it was found that over 9.5 hours of sedentary behavior during waking hours is associated with a higher risk of mortality compared to 7.5 hours¹. In addition to sedentary behavior, a maximum risk reduction concerning LPA was found at 6.3 hours per day and for MVPA approximately 23 minutes. It is important that MPVA is performed in bouts > 10 minutes since bouted MVPA is associated with more reduction of all-cause mortality and frailty^{1,2}. The results in my thesis suggest that people with stroke are at high risk for all-cause mortality based on their high amounts of sedentary behavior, low amounts of LPA and on the low amounts of MVPA¹. Therefore, it is expected that improving movement behavior in people with stroke will have considerable health benefits. In our sample, 43% of the total sedentary time was accumulated in bouts \geq 30 minutes. Currently, cut-off values regarding interrupting sedentary behavior are lacking. However, in a cohort including older adults (older than 60 years) participants spent 34% of their sedentary time in sedentary bouts \geq 30 minutes³. This implicates that people with stroke are accumulating their sedentary time in longer prolonged bouts compared to older adults people with other chronic diseases.

When looking at the results of the movement behavior change of people with stroke within the first two months after discharge, unexpectedly, only a small increase of LPA and a small decrease of sedentary behavior were found. No specific subgroups were identified showing a change in their movement behavior or any aspect of it. Earlier research showed similar results, suggesting a reasonably stable movement behavior up to one year after stroke⁴⁻⁶. An explanation could be that the main focus in care in the subacute phase after stroke is to regain capacity (physical functioning), and less attention is paid to behavioral movement change in the home-setting. Next to regaining physical functioning, the focus of physiotherapy in the stroke services in the Netherlands (like Fit stroke groups) is on improving MVPA by supervised training⁷. However, considering the movement behavior of patients with stroke, the question is whether interventions should focus on reducing sedentary behavior instead of focus on the increase of physical activity.

Movement behavior outcomes

Instead of using separate single movement behavior outcomes, as is generally used in literature, in this thesis, we combined these single movement behavior outcomes in patterns, giving more valuable information on the total movement behavior of patients with stroke. To compose these patterns, an extensive set of movement behavior outcomes was used as recommended by Byrom et al., namely average time per day in sedentary behavior, LPA, MPVA, and MVPA accumulated in bouts \geq 10 minutes, accumulation of sedentary behavior; sedentary behavior accumulated in bouts \geq 5, \geq 30 and \geq 60 minutes,

weighted sedentary bout length, maximum sedentary bout length and the fragmentation index⁸. After compressing the movement behavior outcomes, the three components were identified characterized by 1) total time spent in sedentary behavior, LPA, and MVPA, 2) MVPA accumulated in bouts ≥ 10 minutes, and 3) bouted sedentary behavior. These three components seem to reflect the habitual movement behavior and are able to distinguish movement behavior patterns. Based on the results of our study and the fact that some of these outcome measures were strongly correlated (such as (the weighted median sedentary bout, sedentary behavior accumulated in bouts ≥ 5 minutes, ≥ 30 minutes and ≥ 60 minutes) or difficult to interpret (such as fragmentation index), we recommend for future research to include the following 5 single movement behavior outcomes to provide insight in habitual movement behavior: total time spent in sedentary behavior, LPA, MVPA, MVPA accumulated in bouts ≥ 10 minutes, and Sedentary behavior accumulated in bouts ≥ 30 minutes.

Three distinct movement behavior patterns

In chapter 6, three different movement behavior patterns were distinguished in people with stroke who returned home: 1. Sedentary exercisers (22%), 2. sedentary movers (46%), and 3. sedentary prolongers (32%). Sedentary exercisers spent 63% of the time in sedentary behavior, 27% in LPA, and 10% in MVPA. In addition, they spent >42 minutes per day in MVPA accumulated in bouts of ≥ 10 minutes, and they interrupted their sedentary time often. Only 36% of their sedentary behavior was spent in long prolonged bouts (>30 minutes). The second group, sedentary movers, spent 63% of the time in sedentary behavior, 34 % in LPA and 3% in MVPA. Sedentary movers spent hardly any time in MVPA accumulated in bouts ≥ 10 minutes. In total, 38% of their sedentary behavior was spent in long prolonged bouts (>30 minutes). The third group, sedentary prolongers, spent 77% of the time in sedentary behavior, 20% in LPA and 3% in MVPA. Sedentary prolongers spent hardly any time in MVPA accumulated in bouts of ≥ 10 minutes and 56% of their sedentary behavior was spent in long prolonged sedentary bouts (>30 minutes).

The differences between these three distinct movement behavior patterns seem to be clinically relevant. Within the recent meta-analysis of Ekelund et al. included 36.000 adults, the dose-response relations of sedentary behavior, LPA and MVPA and all-cause mortality were investigated and are presented in respectively figure II, III and IV¹. Per figure, the relationship between the risk of premature mortality and the amount of sedentary, LPA and MVPA is shown. Within these figures, we show the outcomes of the movement behavior pattern which were identified in this thesis. Regarding sedentary behavior, all three movement patterns showed unfavorable behavior (see figure II). However, the difference in sedentary time between sedentary movers and sedentary exercisers versus sedentary prolongers is over two hours, indicating a higher mortality ratio in the last group.

Comparable differences can be seen between the movement behavior pattern for LPA and MPVA (figure III and IV respectively) and leading to differences in the mortality ratios per group. This confirms the clinically relevant differences between the three composed movement patterns. The figures represent the mortality ratios for three separate single movement behavior outcomes. When combining single movement behaviors in movement behavior patterns, it can be expected that more precise mortality ratios can be calculated for each patient with stroke.

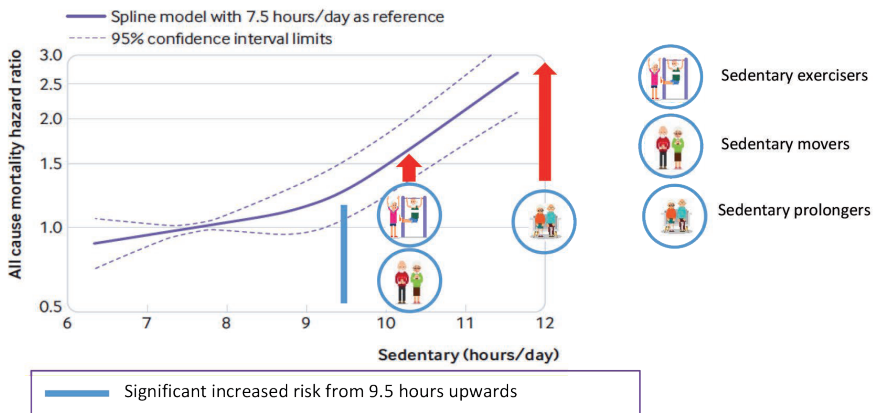


Figure II. Dose-response associations between sedentary behavior and all-cause mortality reprinted from Ekelund et al. (1) including a representation of the amount of time spent in sedentary behavior per movement behavior pattern. The movement behavior patterns were identified in this thesis.

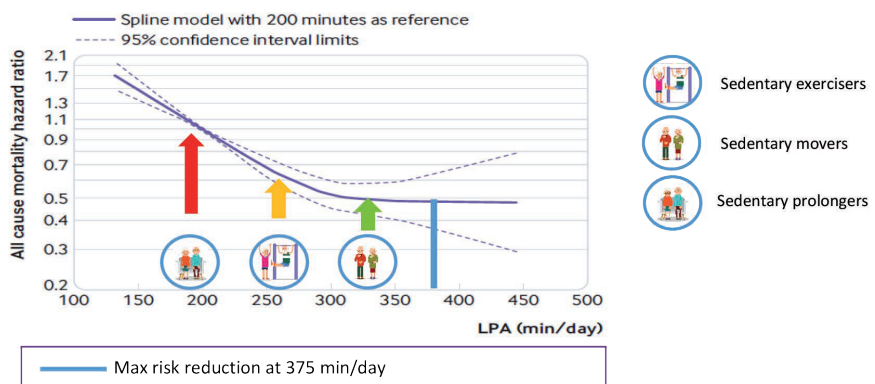


Figure III. Dose-response associations between light physical activity (LPA) and all-cause mortality reprinted from Ekelund et al. (1) including a representation of the amount of time spent in LPA per movement behavior pattern. The movement behavior patterns were identified in this thesis.

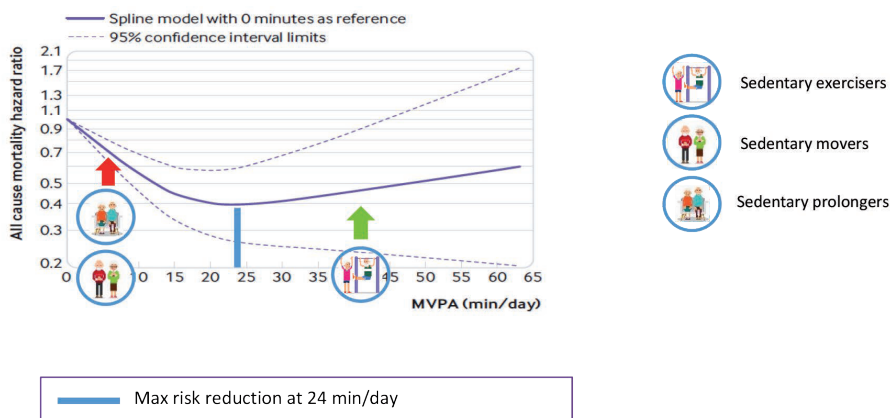


Figure IV. Dose-response associations between moderate-to-vigorous physical activity (MVPA) and all-cause mortality reprinted from Ekelund et al. (1) including a representation of the amount of time spent in MVPA per movement behavior pattern. The movement behavior patterns were identified in this thesis.

Movement behavior patterns and associations

Apart from composing the movement behavior patterns, we were interested in the patients' characteristics for each movement behavior pattern (chapter 6). It appeared that sedentary exercisers were younger, had fewer packyears, were light drinkers and had higher levels of physical functioning. On the other hand, sedentary movers had less severe stroke symptoms, had lower levels of physical functioning but had higher levels of self-efficacy. Sedentary prolongers had more severe stroke symptoms, more pack-years and lower levels of self-efficacy.

Based on our results, it seems that the movement behavior of sedentary prolongers is more related to personal factors such as self-efficacy and habitual physical activity before stroke compared to factors such as physical impairments, cognitive problems, and stroke severity. Although stroke severity and physical impairment were more prevalent in sedentary prolongers, the association was weak. In a previous study with a comparable cohort, a comparable weak association between higher stroke severity and high amounts of sedentary behavior was found⁹. Based on these results, it can be concluded that unfavorable movement behavior patterns are not restricted to persons with more severe stroke symptoms, but can also be present in persons with less severe stroke symptoms. Therefore, attention should be paid in clinical care to assess the movement behavior of patients with stroke, independent of their stroke severity.

Earlier research shows the complexity of associations with sedentary behavior. The most essential reported associations factors in earlier research include professional level,

occupational setting, and the family setting. In older adults, environment and perceived support from municipal authorities in promoting active living were found to be directly associated with sedentary behavior. This environmental and municipal support seems to replace the social context people experienced through work or family in earlier years.¹⁰ Therefore, it is recommended that health care professionals include a quick scan of these aspects (e.g., what are people doing during the day? And how do they interact with their social environment?) in the screening of people with stroke being potentially highly sedentary.

Prevention of decline in physical functioning in people after stroke

In our review (chapter 2), it was found that twelve to forty percent of people with stroke decline in their activities of daily living (ADL) status during the first three years after stroke. In total, nine factors were associated with ADL decline: dependence in ADL, impaired motor function of the leg, insurance status, living alone, age ≥ 80 , being inactive, having impaired cognitive functioning, symptoms of depression, and fatigue. The results of our cohort (chapter 7) show that people's movement behavior pattern is associated with the course of physical functioning. The physical functioning of sedentary exercisers remained stable during the first year of returning home. Both sedentary movers and prolongers improved their physical functioning within the first six months and declined afterward. Additionally, sedentary prolongers seemed to decline more in physical functioning compared to sedentary movers over time. In conclusion, highly sedentary people have an unfavorable course of physical functioning over time compared to individuals with higher amounts of physical activity.

Although our review showed nine factors associated with functional decline, in literature is limited evidence available. So far, only small number of factors have been investigated. Within the studies included within our systematic review, the focus was mainly on physical and stroke-related factors. In addition to these factors, research investigating personal and environmental factors is lacking and could be of added value. To improve generalizability, research investigating functional decline should also include persons with less severe stroke symptoms and not only rehabilitation populations. The people included in the RISE cohort fulfill these requirements: they had mainly minor stroke symptoms but showed a functional decline in the long-term in sedentary movers and sedentary prolongers.

In conclusion, it is recommended that people with stroke are being monitored on a regular base, both on movement behavior and physical functioning. Preferably, this monitoring is incorporated in the current cardiovascular risk management programs delivered by assistant practitioners. To realize this, monitoring physical functioning needs to be not time-consuming and with a low administrative burden for the assistant practitioner. The Late-

Life-Function and Disability Instrument (LLFDI) Computer Adaptive Test (chapter 3) can be a helpful tool. Another example of a comparable instrument is the Patient-Reported Outcomes Measurement Information System global health (PROMIS - GH) which was recommended to obtain physical functioning¹¹. PROMIS tools exist in computer adaptive tests and short forms. Advantages of using computer adapted tests, such as LLFDI or PROMIS, are measuring more efficiently, precisely and based on large items banks^{12,13}.

Changing movement behavior

Considering that most patients with stroke show unfavorable movement behavior, professional support on movement behavior change is needed. Guidance should be based on the individual's movement behavior pattern^{14,15}. More specifically, to optimize health in sedentary exercisers, the focus should be on increasing the amount of time spent in LPA instead of being sedentary. Since their sedentary behavior is comparable or even better compared to the general Dutch population, we would not recommend to include this group in health interventions¹⁶. Self-management and freely available eHealth interventions might be a good option to support this group to decrease sedentary time and maintain physical activity levels over time. For sedentary movers, increasing time spent in MVPA seems to be the target behavior. Increasing levels of MVPA will lead to more health benefits and might counteract the high amounts of sedentary behavior¹⁷. Finally, for sedentary prolongers improving levels of MVPA seems to be too challenging since they have barely any activity at all. Therefore, the target behavior for sedentary prolongers should be on reducing and interrupting sedentary behavior. However, besides movement behavior, the importance of other health behaviors should not be overlooked.

In chapter 8, the first steps were undertaken to identify intervention functions, behavior change techniques, and modes of delivery, which should be included in a behavioral change intervention aiming to reduce sedentary behavior. The literature indicates a high potential of persuasive eCoaching in which technology is used during coaching to motivate and stimulate people to change attitudes, behavior and rituals¹⁸. The integration of eCoaching technology within face-to-face interventions by a health professional is called blended care. For example, self-monitoring, in combination with an eCoachings app, is embedded within the face-to-face guidance of a physiotherapist. The three treatment modalities are not self-contained but complementary to each other.

Methodological considerations

Study population

Our cohort is one of the first studies investigating movement behavior in the total stroke population, whereas most research focused only on people who receive rehabilitation care. In the RISE-cohort study, participants were recruited from four stroke-units in the Netherlands. Patients included when they returned home from the hospital. The majority of the population (74%) were directly discharged to the home setting, 12% first went to inpatient rehabilitation and 14% were discharged to geriatric rehabilitation. These percentages are comparable to another large cohort study with similar patient characteristics conducted in the Netherlands, the Restroke4Stroke Cohort Study which included the first participant in 2011¹⁹.

Movement behavior and variables measured

In movement behavior research, the standardization of definitions, used accelerometers, and movement behavior outcomes differ, and a consensus on these topics has not yet been reached. Therefore, it is difficult to compare studies. We decided to use the consensus terminology as introduced by Tremblay et al. for the definition of movement behavior²⁰. To improve the comparability of studies, the use of this definition is highly recommended. In addition, we used the definition of sedentary behavior that emerged out of this consensus project, namely any waking behavior characterized by an energy expenditure of 1.5 or fewer MET while in sitting, lying or reclining posture²¹. Within previous studies sleeping time was included in sedentary behavior. However, sleeping is a different behavior and should be investigated as a separate behavior.

The identified movement behavior patterns are based on participants who were included in the RISE cohort study. However, external validity needs to be confirmed. Investigating movement behavior patterns in other stroke population can confirm the external validity of the patterns.

Clinical implications

Movement behavior in people with stroke can be optimized to gain sustained health benefits. However, changes in practices are needed to support people with unfavorable movement behavior. Based on the RISE-study, several clinical implications can be given.

1. Risk stratification in this thesis on unfavorable movement behavior patterns in people with stroke showed that unfavorable movement behavior is not only a problem in people with severe stroke symptoms. People with less severe stroke symptoms (walk and talk group) also have unfavorable movement behavior patterns. This should not be overlooked.
2. Implementing the use of an accelerometer to objectify movement behavior pattern in current care is the best option since a sufficiently accurate prediction model or screening tool is lacking.
3. Self-efficacy was found to be low in sedentary prolongers. Improving levels of self-efficacy might be an important target supporting behavioral movement change. Overall personal factors and environmental factors seem to play an important role in unfavorable movement behavior, such as 'what are people doing during the day?' and 'how do they interact with their social environment?'
4. Evaluating our results showed that a substantial proportion of 'sedentary prolongers' and 'sedentary movers' received no care focussed on changing lifestyle (including movement behavior). Within the follow-up visit six weeks after discharge from the hospital by a nurse specialist, physician assistant, or rehabilitation physician screening of movement behavior patterns can be done in addition to screening depressive symptoms, anxiety, cognitive complaints, caregiver burden and, ADL and participation restriction. The screening forms a starting point. Questions about smoking (or past smoking), the level of self-efficacy and pre-morbid physical activity can help to identify people who are at risk. People suspected to have unfavorable movement behavior can be referred to a physiotherapist independent of physical problems because of the stroke.
5. Supporting sedentary exercisers, sedentary movers, and sedentary prolongers in changing their movement behavior, ask for personalized behavioral change interventions. Based on the movement behavior of people with stroke, the target behavior can be selected. Remaining active and slightly reducing sedentary behavior in sedentary exercisers can optimize their health. Addressing the importance of reducing and interrupting sedentary behavior and providing tools to increase the amount of physical activity might optimize

their behavior. Improving the amount of MVPA can provide health benefits in sedentary movers. Sedentary prolongers are barely active, reducing and interrupting sedentary behavior seems to be achievable in people with this movement behavior

6. The improvement of physical activity and the reduction of sedentary behavior seems to be difficult. Blended movement behavioral change interventions are needed incorporating eCoaching technology, self-monitoring embedded within the face-to-face guidance of a physiotherapist.
7. Unfortunately, a substantial part of people with stroke decline in terms of physical functioning. People with stroke are included in the cardiovascular risk management program delivered by assistant practitioners. Currently, aspects as BMI, blood pressure, medication, smoking and exercising are discussed. In addition, more stroke-specific aspects as cognition, mood, caregivers, and participation can be included and based on the results of this thesis movement behavior and physical functioning. It is recommended that people with stroke are being monitored on a regular base, including movement behavior and physical functioning.
8. Definitely, every movement counts. All intensities of physical activity, including LPA, provide health benefits especially in those who are barely active.
9. Yet, a behavioral change intervention, directed at reducing and interrupting sedentary behavior in people with stroke is lacking. Behavior change techniques recommended to include in a behavioral change interventions are, goal-setting, action-planning, social support, problem solving and self-monitoring.

Educational implications

Alongside changes in practice, educational changes are needed. Citizens are responsible for their own (un)health(y) behaviors, including unfavorable movement behavior, and need to self-manage their care. The Council for Public Health care in the Netherlands advocates a change from disease management to health behavior management (van Ziekte en Zorg naar Gezondheid en Gedrag). Healthcare professionals, insurance companies, and employers need to encourage and facilitate citizens' own preventive efforts and offer collective (secondary) prevention. However, people with a chronic disease such as stroke need to be supported by how to self-manage their life with the consequences of their disease. A focus on self-management support by physiotherapists requires an essential shift in the professional attitude of physiotherapists. Therefore it is suggested that physiotherapists will be enablers who can coach and guide the real expert of his or her life, who is the patient. The patient is the expert about his/her own life, lifestyle, motivators, and choices in life. Therefore, coaching skills and skills to support self-management in patients are important to be included in the education system.

There is room for improvement regarding the content of educational programs. To be able to provide behavioral change interventions, specific competencies are needed. Physiotherapists are expected to provide physical activity promotion which is essential for patients²². However, physiotherapists are hesitant to provide movement behavioral change interventions since they prefer supervised interventions, have a lack of self-confidence, have a low level of knowledge, or lack didactic skills to provide behavioral change interventions^{23,24}. Although educational programs include behavioral change interventions and disease prevention within the curricula²⁵, changing movement behavior is mainly addressed in a theoretical manner. Up till now, limited attention has been paid to practicing it as a skill. Therefore, it is advisable to train behavioral movement change as a total concept.

Also, using technology, including eHealth and mHealth, in bachelor educational programs is a great opportunity, as students are possible early adaptors and change agents in practice²⁶. However, teaching eHealth in physiotherapy curricula is currently lacking^{27,28}. Students and current health care professionals can highly benefit from skills to find, understand, apply, and investigate eHealth innovations.²⁹

Suggestions for future stroke research

Based on the RISE study, several suggestions for future research can be made. Whereas this thesis focused on movement behaviors (sedentary behavior, LPA, and MVPA) during waking hours, it is recommended to include sleep in future studies. When sleep is included, 24 hours of (non)movement continuum is complete. A new approach is the 24 hours activity cycle model³⁰. This model provides a holistic approach to the four (non) movement behaviors (sleep, sedentary behavior, LPA, and MVPA) instead of a single behavior focus such as improving only MVPA. This model can guide future research and provide relevant evidence that can be used in future personalized behavioral change interventions. For example, research questions determining the threshold for sedentary behavior regarding optimal health, the optimal balance between sleep, sedentary behavior, LPA and MVPA³⁰, and if better sleeping quality affects the time spent sedentary, will provide vital evidence.

Currently, only two pilot studies aiming to reduce sedentary behavior have been performed^{31,32}. Therefore, more research is needed to develop and investigate effective interventions, aiming to reduce and interrupt sedentary behavior. Traditionally a randomized controlled trial (RCT) is the gold standard to study the effectiveness of an intervention. However, an RCT will be challenging to perform since physiotherapists do not feel confident yet in delivering behavioral change interventions. Therefore, using a multiple case design might a good alternative in which the intervention is delivered by well-trained physiotherapists might provide valuable information about the preliminary effectiveness of such a behavioral intervention.

Conclusion

Three distinctive movement behavior patterns are identified in people with stroke returning to their home-setting. These patterns seem to require a tailored approach, in which different target behavior and content of intervention seem to be needed. An unfavorable movement behavior pattern, with less physical activity and high sedentary behavior, is associated with a functional decline in the long-term. Secondary prevention using a behavioral approach to change movement behavior seems to be indicated in people with stroke who have an unfavorable movement behavior pattern.

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CHAPTER 10



SUMMARY

NEDERLANDSE SAMENVATTING

DANKWOORD

CURRICULUM VITAE

LIST OF PUBLICATIONS

Summary

Globally, stroke affects 16 million individuals every year. Patients who survive a stroke are at high risk for recurrent stroke and other cardiovascular events. In the next decades, the prevalence of stroke is expected to increase worldwide, highlighting the need for effective disease management and secondary prevention strategies. Sufficient amounts of physical activity (PA) can reduce the risk of first-ever stroke, risk of recurrent stroke, and other vascular events. A lack of moderate to vigorous physical activity (MVPA) and high amounts of sedentary behavior (SB) are independent risk factors for all-cause mortality, cardiovascular diseases and functional decline. Although the independent health risks of these single behaviors are highlighted in research, these behaviors are not self-contained but cluster in patterns (e.g., high MVPA/high LPA/low SB or low MVPA/low LPA/high SB). There is a growing interest in the optimal distribution of daily activities, more specifically, the interplay between SB and PA levels in people with stroke. Movement behavior patterns reflect the total habitual behavior during waking hours. Currently, specific movement behavior patterns in people with stroke and the associated long-term impact on physical functioning are unknown.

The results are based on the RISE (**R**educing sedentary behavior, **I**dentification of people at risk, in people with **S**troke, **E**ffectiveness in daily living) cohort study, performed between 2015 and 2019. The general aim of this thesis was to investigate movement behavior in people with stroke, the course of movement behavior in the first two months after discharge to the home setting, identify movement behavior patterns and their associations, and its consequences regarding physical functioning. People with unfavorable movement behavior patterns might benefit from tailored movement behavioral interventions to prevent the decline of physical functioning.

The first step, described in **Chapter 2**, was to provide the state of the art in recovery patterns of activities of daily living after stroke. In the literature, a hypothetical functional recovery model after stroke was launched, postulating that recovery of body functions and activities reaches a plateau phase between three and six months post stroke. Six months after stroke, it is hypothesized that some patients decline, while on average, patients remain stable or improve. Within this chapter, a meta-analysis was performed on the course of activities of daily living (ADL). The main finding was that we were able to confirm the hypothetical recovery model. Between stroke occurrence and three months afterwards, most of the recovery occurs. In general, a plateau was reached somewhere between three and six months. After this period, three ADL trajectories can be discerned: 1. improvement of ADL status; 2. Stable ADL status, and 3. decline in ADL status. Within the first three years, a proportion of 12 to 40% of people with a first-ever stroke declined in ADL status. With the

same study, we conducted qualitative analyses regarding factors associated with a decline in ADL status. Only five studies investigated factors associated with a decline in ADL. A decline in ADL status was found to be ADL dependent, and impaired motor function of the leg was found in two studies, resulting in moderate evidence. Other factors were found in one study. Therefore, limited evidence was found for having no insurance, living alone, age ≥ 80 , being inactive, impaired cognitive function, presence of depression and presence of fatigue.

The majority of people with stroke will return to the home setting after their first-ever stroke. Since we found in our review that a substantial number declined in ADL status within the first three years after stroke, a measurement tool focusing on ADL and participation is needed. In addition, such tools need to be sensitive to change and have a low burden for patients and health care professionals. Existing instruments measuring ADL status and participation have large ceiling effects, give a rather rough impression, and are fixed forms, whereas some questions are not applicable for individuals and are time-consuming to fill out. Computerized adaptive testing can overcome these limitations. In **Chapter 3**, the Late-Life Function and Disability Instrument-CAT version (LLFDI-CAT) was investigated. The LLFDI-CAT measures two domains, activity limitations and participation restrictions, and was developed within gerontology research. The LLFDI-CAT has a database with 137 questions in the activity limitations domain and 55 in the participation domains. Questions are selected based on the answer given to the previous question. The instrument is completed after reaching a predefined stopping rule. The stopping rules used in this chapter were when the maximum number of ten questions was reached or a standard error of measurement of 3.0 was exceeded. The LLFDI-CAT has not yet been evaluated in the stroke population. Therefore, the aim was to investigate the concurrent validity, floor and ceiling effects and responsiveness of both domains of the LLFDI-CAT in first-ever stroke survivors discharged to their home setting. The LLFDI-CAT seems to be a valid instrument, and the instrument can detect change over time. Only a ceiling effect in the participation restriction domain of 15% was found at six months after discharge to the home setting. The LLFDI-CAT was found to be useful for both research and clinical practice.

The best way to measure movement behavior is objectivity by an accelerometer. The commercially available Activ8 accelerometer can differentiate between the different elements of movement behavior. The Activ8s hardware is relatively cheap, the software is available for free, it is comfortable to wear and is able to monitor continuously up to thirty days. Additionally, Activ8 can provide real-time feedback on behavior, which seems to be promising when changing movement behavior. In a healthy population, Activ8 showed promising results in healthy subjects. However, before using the device in a stroke patient, it should be investigated. In **Chapter 4**, the criterion and structural validity of the Activ8 accelerometer were investigated while assessing sedentary behavior, standing, walking

and cycling in community walking people with stroke. The criterion validity of the Activ8 accelerometer was investigated by asking participants to perform consecutive tasks using a standardized protocol. The output of Activ8 was compared with video data. Structural validity was investigated using the MoveMonitor accelerometer as a reference. Participants wore both devices for two days. Sensitivity scores ranged from 91.9 to 76.3 for sedentary behavior and cycling, respectively. The ICC scores between Activ8 and MoveMonitor varied between 0.76 and 0.91. Activ8 was found to be a valid tool for the continuous monitoring of sedentary behavior, standing, walking and cycling in community walking people with stroke. Therefore, the device was used in the RISE study to investigate the movement behavior of people with stroke.

The period shortly after stroke seems to be crucial to change movement behavior. Most recovery of function occurs within the first week after stroke, when most people still receive professional care and motivational preparedness to achieve the desired behavior change is potentially high. Therefore, in **chapter 5**, the course of movement behavior within the first two months after discharge to the home setting was investigated. Because stroke recovery is not a one-size-fits-all-principle, subgroup trajectories were investigated to objectify if possible subgroups changed their movement behavior. In total, five movement behavior outcomes were investigated (sedentary behavior, light physical activity (LPA), moderate-to-vigorous physical activity (MVPA), MVPA accumulated in bouts ≥ 10 minutes and the weighted median sedentary bout). In this chapter, a sample ($n=140$) of people who were discharged directly to the home setting was included. In general, participants spent an average of 67% per day in sedentary behavior, 28% in LPA and 5% in MVPA. Overall, it seems that people with stroke are highly sedentary compared to healthy peers. The amount of time spent in MVPA seems to be relatively high; however, this was due to a small group that was highly active. Bouted MVPA barely occurred, and people with stroke seem to interrupt their sedentary behavior often. Only a small decrease in sedentary behavior was noted, and an increase in light physical activity was noted. All other movement behavior outcomes remained stable. Although we found subgroups per movement behavior outcome (e.g., highly sedentary and less sedentary people with stroke and inactive and active) in these subgroups, no changes occurred. We investigated whether individual patients were distributed to different subgroups per movement behavior outcome; for example, 54% of the people who were highly sedentary were nonmovers, but only 36% of the highly sedentary people were inactive. Therefore, the next step is to investigate whether movement behaviors cluster in patterns (e.g., sufficient amount of MVPA and sedentary or inactive and not sedentary).

The identification of movement behavior patterns in people with a first-ever stroke is described in **chapter 6**. A cross-sectional study ($n=190$) was performed. To objectify

movement behavior patterns, participants wore the Activ8 accelerometer for two consecutive weeks. Demographics, stroke care, physical functioning and psychological, cognitive and social factors were obtained. Differences between factors associated with a single movement behavior pattern were investigated. On average, the accelerometer was worn for 13.7 hours per day. The average movement behavior of the participants was 9.3 sedentary hours, 3.8 hours of light physical activity and 0.6 hours of moderate-vigorous physical activity. In total, three movement behavior patterns emerged in people with stroke (see table 1, movement behavior outcomes per pattern). Sedentary exercisers (22.6%) were sedentary; however, sedentary time was often interrupted, and overall, these participants were sufficiently active. Sedentary movers' (45.6%) sedentary behavior was comparable to sedentary exercisers' sedentary behavior. However, this group was inactive. The time sedentary exercisers spent in MVPA, sedentary movers spent in light physical activity. Sedentary prolongers (31.6%) were highly sedentary, accumulated their sedentary time in long prolonged bouts and were physically inactive. Associations with movement behavior patterns were investigated. Significant associations with sedentary exercisers were lower age, fewer pack-years, light drinking and higher physical functioning. For sedentary movers, these associations were less severe stroke symptoms, lower physical functioning and higher levels of self-efficacy. Associations with sedentary prolongers were low levels of self-efficacy, more pack-years and more severe stroke symptoms.

Table 1. Movement behavior outcomes per pattern.

Movement behavior outcome Mean (SD)	Sedentary exercisers (n=43)	Sedentary movers (n=87)	Sedentary prolongers (n=60)
Sedentary behavior (hours/day)	9.0 (1.6)	8.4 (1.5)	10.7 (1.4)
Percentage sedentary behavior	63.6 (8.7)	62.6 (9.9)	77.6 (5.5)
LPA (hours/day)	3.8 (1.2)	4.6 (1.5)	2.7 (0.8)
Percentage LPA	26.7 (8.2)	34.2 (10.2)	19.7 (5.2)
MVPA (hours/day)	1.4 (0.4)	0.4 (0.3)	0.4 (0.3)
Percentage MVPA	9.7 (2.6)	3.2 (2.1)	2.8 (1.9)
Sedentary bouts ≥30 minutes (hours/day)	3.2 (1.0)	3.2 (1.0)	5.9 (1.1)
MVPA bouts ≥10 minutes (hours/day)	0.7 (0.3)	0.1 (0.1)	0.1 (0.1)

SD= standard deviation, LPA= light physical activity, MVPA= moderate-vigorous physical activity, min= minutes

In our review, we found that being inactive was one of the associating factors. However, the long-term consequences of movement behavior patterns found in chapter 6 in people with stroke are unknown. Therefore, we investigated the relationship between movement behavior patterns and the course of physical functioning in the first year after returning home. **Chapter 7** describes the outcomes of the prospective longitudinal study

(n=200). Participants' physical functioning was assessed within three weeks, at six months and one year after discharge. Physical functioning was subjectively measured with the Stroke Impact Scale (SIS) 3.0 and objectively with the five-meter walk test (5MWT). The association between movement behavior patterns and the course of physical functioning was determined using longitudinal generalized estimating equation analyses. Physical functioning remained relatively stable during the first year after stroke in sedentary exercisers. Physical functioning measured with the SIS improved during the first six months after discharge in sedentary movers and sedentary prolongers and deteriorated in the following six months. Although the course of physical functioning objectified with the 5MWT in sedentary movers and sedentary prolongers showed a similar pattern compared to the SIS, individual diversity changes showed no significance. Physical functioning at baseline and in the course of the first year after stroke differ between movement behavior patterns. Therefore, it seems that physical functioning outcomes at baseline are decisive for the course of physical functioning within the first year. The need for interventions to prevent a decline in physical functioning is urgent. Therefore, tailored interventions for both sedentary movers and sedentary prolongers are needed. Based on the movement behavior pattern, individuals will have different target behaviors. Sedentary movers should be encouraged to reach sufficient amounts of MVPA, and sedentary prolongers should focus on interrupting and decreasing sedentary behavior.

Since reducing and interrupting sedentary behavior is a new target in stroke rehabilitation, movement behavioral interventions will be needed. In the literature, it was found that targeting sedentary behavior alone is more effective than reducing sedentary behavior and improving the amount of MVPA. Therefore, in **Chapter 8**, we described the first steps of the development of behavioral change interventions to reduce sedentary behavior in people with stroke by using the Behavior Change Wheel (BCW). To complete the stages of the BCW, information on understanding the behavior, identifying intervention functions, identifying behavior change techniques (BCTs), and modes of delivery were needed. To acquire this information, for each stage, a literature search was conducted, and nominal group technique (NGT) sessions were conducted to identify BCTs. The NGT sessions were conducted with professionals working with people with stroke and with international researchers working in the stroke or sedentary behavior field. Participants made their choice by rating the BCTs, starting from most important (eight points) down to zero points. In total, 75 eligible BCTs were identified. Five BCTs should always be included: 'goal setting', 'action planning', 'social support', 'problem-solving', and 'restructuring of the social environment'. For patients without cognitive impairments, 'self-monitoring', 'feedback on behavior', 'information about health consequences' and 'goal setting on outcome' were advised to be included, while for patients with cognitive impairments, 'prompts/cues', 'graded tasks', 'restructuring the physical environment' and 'social support practical' should be considered.

Three distinctive movement behavior patterns are identified in people with stroke returning to their home-setting. These patterns seem to require a tailored approach, in which different target behavior and content of intervention seem to be needed. An unfavorable movement behavior pattern, with less physical activity and high sedentary behavior, is associated with a functional decline in the long-term. Secondary prevention using a behavioral approach to change movement behavior seems to be indicated in people with stroke who have an unfavorable movement behavior pattern.

Nederlandse samenvatting

Wereldwijd maken 16 miljoen mensen een beroerte door. Patiënten die een beroerte overleven hebben een groot risico op het krijgen van een tweede beroerte en andere cardiovasculaire aandoeningen. In de komende decennia zal de prevalentie van mensen die een beroerte krijgen wereldwijd toenemen. Dit onderschrijft het belang voor effectieve behandelingen en secundaire preventie. Voldoende fysieke activiteit kan het risico op een eerste beroerte, een tweede beroerte en andere vasculaire aandoeningen reduceren. Te weinig matig of zwaar intensieve lichamelijke activiteit en veel sedentair gedrag zijn, bij patiënten die een beroerte hebben doorgemaakt, onafhankelijke risicofactoren voor vroegtijdig overlijden, cardiovasculaire aandoeningen en fysieke achteruitgang.

Tot nu toe is er bij de bepaling van risicofactoren gekeken naar de afzonderlijk componenten van beweeggedrag (bijv. naar de hoeveelheid matige fysieke activiteit of de hoeveelheid sedentair gedrag). Deze componenten van beweeggedrag staan echter niet op zichzelf maar hangen samen in patronen. Het is bijvoorbeeld een groot verschil of iemand voornamelijk sedentair gedrag vertoont of dat iemand veel sedentair gedrag vertoont maar ook voldoende matige fysieke activiteit uitvoert op een dag. Steeds meer aandacht gaat uit naar de optimale verhouding van sedentair gedrag en de intensiteit van fysieke activiteit gedurende de dag bij mensen die een beroerte doorgemaakt hebben. Op dit moment is het echter nog onbekend wat de specifieke beweegpatronen bij mensen die een beroerte doorgemaakt hebben zijn en hoe deze patronen samenhangen met risicofactoren als fysieke achteruitgang, cardiovasculaire aandoeningen en vroegtijdig overlijden.

De resultaten zoals beschreven in dit proefschrift zijn gebaseerd op de RISE cohort studie (**R**educing sedentary behavior, **I**dentification of people at risk, in people with **S**troke, **E**ffectiveness in daily living), welke uitgevoerd is tussen 2015 en 2019. De vraagstellingen binnen dit onderzoek waren:¹ hoe ziet het beweeggedrag van mensen die een beroerte doorgemaakt hebben eruit in de eerste twee maanden na ontslag uit het ziekenhuis naar huis?;² welke beweegpatronen kunnen geïdentificeerd worden?;³ welke factoren zijn geassocieerd met deze patronen?;⁴ wat is de invloed van een beweegpatroon op het fysieke functioneren in het eerste jaar na de beroerte. De inzichten kunnen bijdragen om op maat gemaakt beweeggedrag interventies te ontwikkelen die achteruitgang in fysieke functioneren tegen gaan.

De eerste stap in dit onderzoek, beschreven in Hoofdstuk 2, was om de laatste inzichten te beschrijven over het herstel van activiteiten van het dagelijkse leven (ADL). In dit hoofdstuk is middels een meta-analyse van 28 studies het verloop van ADL onderzocht. Tussen het ontstaan van de beroerte en drie en zes maanden daarna vindt het meeste herstel plaats in

ADL. Na deze periode werden drie trajecten van herstel gevonden, een groep mensen die nog steeds vooruit gaat, een groep mensen die een plateau bereikt en een groep mensen die helaas achteruitgaat in ADL. Binnen drie jaar na de beroerte ging in totaal 12 tot 40% van de mensen achteruit in ADL. Slechts vijf studies hebben onderzocht wat factoren zijn die geassocieerd zijn met achteruitgang in ADL. Voor ADL afhankelijkheid direct na de beroerte en verminderde aansturing van het been direct na de beroerte werd matig bewijs gevonden. Gelimiteerd bewijs werd gevonden voor geen zorgverzekering hebben, alleenwonend, leeftijd ouder dan tachtig, inactief zijn, verminderd cognitief functioneren, depressiviteit en vermoeidheidsklachten.

De meerderheid van de mensen die een beroerte doorgemaakt hebben gaan na ziekenhuisopname weer naar huis. Omdat een substantieel deel van de mensen achteruitgaat binnen de eerste drie jaar na de beroerte in hun ADL functies en minder in staat zijn te participeren, is het belangrijk om mensen adequaat te volgen op lange termijn. Daarvoor is een meetinstrument nodig gericht op het meten van ADL en participatie. Belangrijk is dat zo'n instrument gevoelig is voor het meten van verandering en niet tijdrovend voor patiënten en zorgprofessionals. Bestaande meetinstrumenten die ADL en participatie meten hebben echter een plafondeffect, geven slechts een ruwe schatting van het functioneren, bevatten een aantal vragen die niet van toepassing zijn op het individu en kosten veel tijd om in te vullen. Middels computer adaptief testen (CAT) kunnen deze problemen voorkomen worden. CAT instrumenten selecteren vragen die worden geselecteerd op basis van het gegeven antwoord op de voorgaande vraag. Daardoor zijn minder vragen nodig om te een vergelijkbare precisie te komen. In hoofdstuk 3 is de Late-Life-Function and Disability Instrument –CAT (LLFDI-CAT) onderzocht. Het doel van deze studie was om de concurrente validiteit, vloer- en plafondeffecten en de responsiviteit voor beide domeinen van de LLFDI-CAT te onderzoeken bij mensen die een beroerte doorgemaakt hebben en terug thuis gekomen zijn. De LLFDI-CAT, ontwikkeld in de gerontologie, meet twee domeinen, te weten: beperkingen in fysieke activiteiten en in participatie. Het domein beperkingen in activiteiten heeft 137 vragen in de database en in het domein van beperkingen in participatie zijn 55 vragen opgenomen. Het instrument is klaar bij maximaal tien vragen per domein of als een standaard meetfout van 3.0 werd overschreden. Dit onderzoek vond dat de LLFDI-CAT een valide instrument is en het instrument kan verandering over tijd meten. Zes maanden na thuiskomst werd een plafondeffect gevonden bij het domein restricties in participatie van 15%. Gebaseerd op de resultaten werd geconcludeerd dat de LLFDI-CAT een bruikbaar instrument is voor zowel onderzoek als de klinische praktijk.

Naast het meten van het activiteiten- en participatieniveau van mensen na een beroerte is het belangrijk om het objectieve beweeggedrag te meten. De beste manier om dit te doen is door te meten middels een accelerometer. De commercieel verkrijgbare Activ8

accelerometer kan differentiëren tussen verschillende elementen van het beweeggedrag. De hardware van de Activ8 is relatief goedkoop, de software is vrij verkrijgbaar, het is comfortabel te dragen en kan zonder de batterij op te laden dertig dagen meten. Daarnaast kan de Activ8 real-time feedback geven op het beweeggedrag, wat een belangrijke gedragsveranderingstechniek is om gedrag daadwerkelijk te veranderen. Voor de populatie na beroerte was de Activ8 nog niet gevalideerd. In hoofdstuk 4 werd daarom de criterium en de structurele validiteit van de Activ8 accelerometer onderzocht bij mensen die een beroerte doorgemaakt hebben en niet beperkt werden in het lopen. De criterium validiteit van de Activ8 werd onderzocht door middel van een strikt protocol dat werd doorlopen door de deelnemers. De output van de Activ8 werd vergeleken met videobeelden. Structurele validiteit werd onderzocht door een vergelijking met een tweede accelerometer die gebruikt werd als referentie, in dit geval de MoveMonitor. Deelnemers droegen beide accelerometers twee dagen. De sensitiviteitscores hadden een range van 91.9 tot 76.3 voor de verschillende houdingen. De intra class correlatie coëfficiënt vergeleken tussen de Activ8 en MoveMonitor varieerde tussen de 0.76 en 0.91. De Activ8 was valide met betrekking tot het continu monitoren van sedentair gedrag, staan, lopen en fietsen in mensen die een beroerte hadden doorgemaakt en daarbij niet beperkt werden in het lopen. Daarom werd de Activ8 gebruikt in de RISE-studie om het beweeggedrag te objectiveren.

De periode kort na de beroerte lijkt cruciaal te zijn om beweeggedrag te veranderen. Het meeste herstel vindt plaats in de eerste weken na de beroerte, mensen ontvangen in die periode meestal nog zorg en de motivatie om te veranderen is nog hoog. Het is echter niet bekend hoe het beweeggedrag van mensen die een beroerte hebben doorgemaakt zich ontwikkelt in de eerste maanden na ontslag vanuit het ziekenhuis naar huis. Herstel na een beroerte is niet een *one-size-fits-all* principe. Daarom werd niet alleen het verloop van de gehele populatie onderzocht maar werd er ook gekeken of er mogelijk subgroeptrajecten waren van mensen die voor- of achteruitgingen in hun beweeggedrag. In totaal werden vijf beweeggedraguitkomstmaten onderzocht (sedentair gedrag, licht intensieve lichamelijke activiteit, matig-tot-zwaar intensieve lichamelijke activiteit, matig-tot-zwaar intensieve lichamelijke activiteit in een periode van tenminste tien minuten aaneengesloten en de gewogen mediane sedentaire periode). In hoofdstuk 5 werden 140 mensen met een beroerte die direct na ziekenhuisopname naar huis ontslagen onderzocht. Gemiddeld waren de deelnemers 67% van de dag sedentair, 28% licht intensief lichamenlijk actief en 5% in matig-tot-zwaar intensief actief. Dat betekent dat mensen die een beroerte hebben doorgemaakt veel tijd sedentair doorbrengen vergeleken met gezonde leeftijdsgenoten. Het sedentair gedrag werd redelijk vaak doorbroken. De gemiddelde hoeveelheid matig-tot-zwaar intensieve lichamelijke activiteit leek relatief veel te zijn, dit was echter toe te schrijven aan een relatief kleine actieve groep. Matig-tot-zwaar intensieve lichamelijke activiteit in een periode van tenminste tien minuten aangesloten kwam nauwelijks voor.

Sedentair gedrag en lichte intensieve lichamelijke activiteit veranderden over de tijd waarbij sedentair gedrag verminderde en lichte intensieve lichamelijke activiteit toenam. De veranderingen waren echter minimaal. Alle andere beweeggedrag uitkomstmaten bleven stabiel. Ook binnen de subgroepen bleef het alle beweeggedrag uitkomsten stabiel. Of mensen nu veel of weinig sedentair gedrag vertonen het gedrag blijft hetzelfde. Binnen dit onderzoek werd verder gevonden dat mensen die veel sedentair gedrag vertoonden zowel voldoende als onvoldoende matig-tot-zwaar intensief lichamelijke activiteit konden zijn. Er zijn dus verschillende beweegpatronen. In hoofdstuk 6 werden de meest voorkomende beweegpatronen geïdentificeerd bij mensen die een beroerte hebben doorgemaakt.

De identificatie van beweegpatronen bij mensen die een eerste beroerte hebben doorgemaakt is beschreven in hoofdstuk 6. Er werd daartoe een cross-sectionele studie (n=190) uitgevoerd. Om beweegpatronen te objectiveren droegen de participanten de Activ8 accelerometer gedurende twee aaneengesloten weken. Daarnaast werden demografische factoren, beroertegerelateerde factoren, fysiek functioneren, en psychologische, cognitieve en sociale factoren gemeten om een mogelijke associatie met de gevonden beweegpatronen te identificeren. Gemiddeld werd de accelerometer 13.7 uur gedragen. Gemiddeld waren de deelnemers gedurende 9.3 uur sedentair, gedurende 3.8 uur licht intensief lichamelijke actief en gedurende 0.6 uur matig-tot-zwaar intensief lichamelijke actief. Er werden daarbij drie beweegpatronen gevonden (zie tabel 1 voor meer gedetailleerde informatie per patroon). ‘Sedentary exercisers’ (22.6% van de deelnemers) waren weliswaar veelal sedentair, echter hun sedentair gedrag werd vaak doorbroken. Ook was deze groep voldoende matig-tot-zwaar intensief lichamelijke actief. Voldoende houdt in dat iemand minstens 150 minuten per week matig-tot-zwaar intensief lichamelijke actief is. ‘Sedentary movers’ (45.6%) vertoonden dezelfde hoeveelheid sedentair gedrag en doorbraken het sedentair gedrag op eenzelfde manier als de sedentaire sporters. Deze groep was echter onvoldoende matig-tot-zwaar intensief lichamelijke actief. Gedurende de tijd dat sedentaire sporters aan matig-tot-zwaar intensief lichamelijke activiteiten spendeerden waren sedentaire bewegers slechts licht intensief lichamelijke actief. De groep ‘sedentary prolongers’ (31.6%) vertoonden veel sedentair gedrag in lange aaneengesloten perioden en daarnaast waren deze deelnemers inactief. Factoren die geassocieerd waren met het behoren tot de groep ‘sedentary exercisers’ waren: jongere leeftijd, minder jaren gerookt, lichte drinkers (gemiddeld 1 consumptie per dag) en een hoger niveau van fysiek functioneren. Factoren geassocieerd met het behoren tot de groep ‘sedentary movers’ waren minder ernstige beroerte symptomen, lager niveau van fysieke functioneren en hogere zelf-effectiviteitsscore. Associërende factoren met het behoren tot de groep ‘sedentary prolongers’ waren lagere zelf-effectiviteitsscore, meer jaren gerookt, en ernstigere beroerte symptomen.

Tabel 1. Beweeggedraguitkomsten per beweegpatroon.

Beweeggedraguitkomsten Gemiddeld (SD)	Sedentary exercisers (n=43)	Sedentary movers (n=87)	Sedentary prolongers (n=60)
Sedentair gedrag (uren/dag)	9.0 (1.6)	8.4 (1.5)	10.7 (1.4)
Percentage sedentair gedrag	63.6 (8.7)	62.6 (9.9)	77.6 (5.5)
LILA (uren/dag)	3.8 (1.2)	4.6 (1.5)	2.7 (0.8)
Percentage LILA	26.7 (8.2)	34.2 (10.2)	19.7 (5.2)
MILA (uren/dag)	1.4 (0.4)	0.4 (0.3)	0.4 (0.3)
Percentage MILA	9.7 (2.6)	3.2 (2.1)	2.8 (1.9)
Sedentaire periode ≥30 minuten (uren/dag)	3.2 (1.0)	3.2 (1.0)	5.9 (1.1)
MILA periode ≥10 minutes (uren/dag)	0.7 (0.3)	0.1 (0.1)	0.1 (0.1)

SD= standard deviatie, LILA= licht intensieve lichamelijke activiteit, MILA= matig-tot-zwaar intensieve lichamelijke activiteit, min= minuten

In de literatuurstudie beschreven in hoofdstuk 2 werd inactiviteit gevonden als een van de factoren geassocieerd met achteruitgang in ADL. De consequenties van beweegpatronen op de langere termijn, beschreven in hoofdstuk 6, waren nog niet bekend in de literatuur. Daarom werd de relatie tussen beweegpatronen en de het beloop van fysiek functioneren in het eerste jaar na thuiskomst onderzocht bij mensen na een eerste beroerte. De uitkomsten van dit prospectief longitudinaal onderzoek (n=200) is beschreven in hoofdstuk 7. Het fysieke functioneren van de deelnemers werd gemeten binnen drie weken na thuiskomst, zes maanden later en een jaar later. Fysiek functioneren werd subjectief gemeten met de Stroke Impact Scale (SIS) 3.0 en objectief met de vijf-meter looptest (5MLT). Middels *generalized estimating equations* werd de associatie tussen beweegpatronen en het beloop van fysiek functioneren onderzocht. Het fysieke functioneren van ‘sedentary exercisers’ bleef in het eerste jaar na de beroerte stabiel. Fysiek functioneren gemeten met de SIS verbeterde tot zes maanden na thuiskomst bij zowel ‘sedentary movers’ als ‘sedentary prolongers’. Tussen zes maanden en een jaar na thuiskomst ging het fysiek functioneren bij deze beide beweegpatronen achteruit. Het fysiek functioneren gemeten met de 5MLT liet eenzelfde patroon zien bij sedentaire bewegers en sedentaire prolongers. Door individuele variabiliteit was dit echter niet significant. Zowel bij thuiskomst als gedurende het eerste jaar is het fysiek functioneren anders tussen de mensen met verschillende beweegpatronen. Het fysiek functioneren bij thuiskomst blijkt voorspellend voor het verloop daarna. Interventies gericht op het voorkomen van achteruitgang in fysiek functioneren zijn dan ook nodig. Het optimaliseren van het beweeggedrag kan mogelijk bijdragen aan het behoud van het fysiek functioneren. Gebaseerd op een individu's beweegpatroon kan een doelgedrag gekozen worden. Voor ‘Sedentary movers’ is het mogelijk haalbaar om voldoende matig-tot-zwaar intensief lichamelijke actief te zijn. ‘Sedentary prolongers’ dienen eerst te focussen op

het doorbreken en verminderen van hun sedentair gedrag om het vertrouwen in eigen kunnen op te bouwen.

Uit onderzoek blijkt dat een primaire focus op het verminderen en doorbreken van sedentair gedrag effectiever is dan de focus op zowel het reduceren van sedentair gedrag als het verbeteren van matig-tot-zwaar intensieve lichamelijke activiteiten. Omdat het doorbreken en verminderen van sedentair gedrag een nieuw doel is binnen de beroerterevalidatie is het ontwikkelen van een gedragsinterventie nodig. In hoofdstuk 8 zijn de eerste stappen beschreven voor het ontwikkelen van een gedragsveranderingsinterventie gericht op het reduceren van sedentair gedrag bij mensen na een eerste beroerte middels het *Behavior Change Wheel* (BCW). Alle stappen binnen het BCW werden doorlopen: inzichtelijk krijgen waarom mensen na een beroerte veel sedentair gedrag vertonen, interventiefuncties selecteren. Ook werden gedragsveranderingstechnieken en de manier waarop de interventie aangeboden werden geïdentificeerd. Om voldoende informatie te vergaren werd een literatuurstudie gedaan en een nominale groep techniek (NGT) sessie gehouden. De NGT sessie werd gehouden bij professionals werkzaam met mensen die een beroerte hebben doorgemaakt en onderzoekers wereldwijd. Deelnemers scoorden de gedragsveranderingstechnieken beginnend bij het meest belangrijk (acht punten) tot de minst belangrijke (1 punt). In totaal werden 75 gedragsveranderingstechnieken gescoord. Vijf gedragsveranderingstechnieken dienen daarbij volgens de deelnemers altijd in een interventie te zitten. Dit waren: 'doelen stellen', 'actieplan maken', 'te boven komen van problemen', 'sociale support' en 'het reconstrueren van de sociale omgeving'. Voor patiënten zonder cognitieve beperkingen dienen 'zelf-monitoring', 'feedback op gedrag', 'informatie over de gezondheidsconsequenties' en 'doelen stellen op de uitkomst' opgenomen te worden. Bij mensen met cognitieve beperkingen dienen 'aanwijzingen en cues', 'gradueel opbouwen van de activiteiten', 'in kaart brengen van de fysieke omgeving' en 'praktische sociale steun' opgenomen te worden.

Samenvattend werden drie kenmerkende beweegpatronen gevonden bij mensen die een eerste beroerte hebben doorgemaakt en ontslagen werden naar de thuissituatie. Deze patronen vragen om een op maat gemaakte aanpak, waarbij verschillende doelgedragingen en inhouden van de interventie nodig zijn. Een ongunstig beweegpatroon met weinig fysieke activiteit en veel sedentair gedrag is geassocieerd met fysieke achteruitgang op de lange termijn. Secundaire preventie met een gedragsgeoriënteerde aanpak om beweeggedrag te verbeteren lijkt geïndiceerd bij mensen na een beroerte met een ongunstig beweegpatroon.

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Curriculum Vitae



Roderick was born on August 19, 1985, in Grijpskerke, the Netherlands. After completing secondary school in 2003 he started studying Physiotherapy at Fontys University of Applied Sciences in Eindhoven. After graduation in 2007, he started working at Libra Rehabilitation & Audiology as a physiotherapist where he guided patients with stroke. Shortly afterwards, these activities were extended by working at the Hospital Elisabeth-Tweesteden in Tilburg. Additionally in 2007 he started studying Clinical Health Sciences, Physiotherapy Science, at Utrecht University.

After graduation he started working as a physiotherapy lecturer at Fontys University of Applied Sciences. Unfortunately in 2012 his activities in clinical practice ended because the combination of applying research, education and performing clinical care was no longer feasible. In 2014 he started his PHD study 'Movement behavior in people with a first-ever stroke – the RISE-cohort study' at the University Medical Center Utrecht.

Currently Roderick is education program coordinator of the premaster Clinical Health Sciences at Utrecht University/University Medical Center Utrecht. He is project manager at Fontys School for Allied Health Professions where he develops learning communities in real life (allied) healthcare settings. Within the learning communities new knowledge and health care innovations are developed in collaboration with students, citizens, patients, healthcare professionals, lecturers and researchers. As lecturer and researcher he is involved in the self-management research group at Fontys University of Applied sciences, the center for physiotherapy research and innovation in primary care, Leidsche Rijn Julius Health Care Centers and physiotherapy sciences at University Medical Center Utrecht. His research focuses on guidance of people with chronic diseases in self-management and maintaining good health. Roderick will continue his work as a project manager and postdoctoral researcher to optimize and maintain good health in people with chronic diseases with a specific focus on movement behavior.

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Wondergem R.²⁰¹⁹ Surviving a PhD – a qualitative single case study. March. University of Utrecht, Health Science today, Utrecht (the Netherlands), presentation.

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Wondergem R, Pisters MF, Wouters EJM, de Bie RA, Visser JMA, Veenhof C.²⁰¹⁹Validation and responsiveness of the late-life function and disability instrument computerized. WCPT, may, Geneve (Switzerland) poster presentation.

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Wongergem R, Pisters MF, Veenhof C, Hendrickx W, English C, Visser JMA²⁰¹⁹. Symposium Beweggedrag van mensen na een beroerte. Fontys University of Applied Science, July, Eindhoven (The Netherlands).

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Wongergem R.²⁰¹⁹ Movement behavior how to deal with in practice. Maastricht University, September, Maastricht (The Netherlands), presentation.

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Wongergem R, Pisters MF, Wouters EJM, de Bie RA, Veenhof C, Visser JMA.²⁰¹⁹. The course of physical functioning in the first year after stroke depends on peoples movement behavior patterns –a prospective study. DVF, November, Den Bosch (the Netherlands), platform presentation & poster presentation.

Wongergem R, Hendrickx W.²⁰¹⁹ Sustainable behavioral change in people with stroke. Leuven University, (Belgium), presentation and workshop.

Wongergem R²⁰²⁰ Movement behavior in people with stroke and sustainable behavioral change. January. University of Applied Sciences Utrecht, Utrecht (The Netherlands) Presentation and workshop.

Wongergem R²⁰²⁰ Beweggedrag bij mensen na een beroerte. Nederlands Paramedisch instituut, Apeldoorn (The Netherlands), presentation.

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Awards

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Best Poster Award, CVA kennisnetwerk Congress, 2019.

Best poster Award, World Confederation Physiotherapy Congress, 2017.



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