

# HEALTH-RELATED BEHAVIOR CHANGE AFTER TIA OR ISCHEMIC STROKE

DORIEN BROUWER- GOOSSENSSEN





## **Health-related behavior change after TIA or ischemic stroke**

Dorien Brouwer-Goossensen

Financial support of Erasmus MC and Stichting Neurovasculair Onderzoek Rotterdam is gratefully acknowledged.

The MOTIVE study was funded by the Evidence Based Care for Nurses fund of Erasmus MC.

Cover & Layout by: Birgit Vredenburg | [Persoonlijkproefschrift.nl](http://Persoonlijkproefschrift.nl)

Printed by: Ridderprint | [ridderprint.nl](http://ridderprint.nl)

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# **Health-related Behavior Change after TIA or Ischemic Stroke**

Onderzoek naar leefstijlverandering na een TIA of herseninfarct

## **Proefschrift**

Ter verkrijging van de graad van doctor aan de  
Erasmus Universiteit Rotterdam  
op gezag van de rector magnificus  
prof.dr. R.C.M.E. Engels  
en volgens het besluit van het college voor Promoties.

De openbare verdediging zal plaatsvinden op  
woensdag 18 november om 11.30 door

Dorien Brouwer-Goossensen  
geboren te Leiderdorp

**Erasmus University Rotterdam**



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Copromotor: dr. M.H. den Hertog

*You make me brave*

Bethel Music





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# General introduction





## INTRODUCTION

*“How can we support patients in changing their lifestyle after a TIA or minor ischemic stroke?”*

My PhD project started with this question. Each year over 400 patients visit our outpatient clinic after a transient ischemic attack (TIA) or ischemic stroke. As neurovascular nurse practitioner I want to be able to reduce the risk of recurrent stroke or TIA not only by prescribing medication, but also by promoting health-related behavior. During the past fifteen years I have done my best to optimally support these patients, but at times have experienced a sense of powerlessness in guiding the patients to adopt more healthy behavior. It has struck me that some patients quit smoking immediately whereas others tell me “that the stroke isn’t bad enough to stop smoking”. Which factors play a role and how can the nurse practitioner support patients in this process? As very little was known about factors that played a role, effective interventions and the optimal timing of an intervention, I decided to study health-related behavior change after TIA or ischemic stroke.

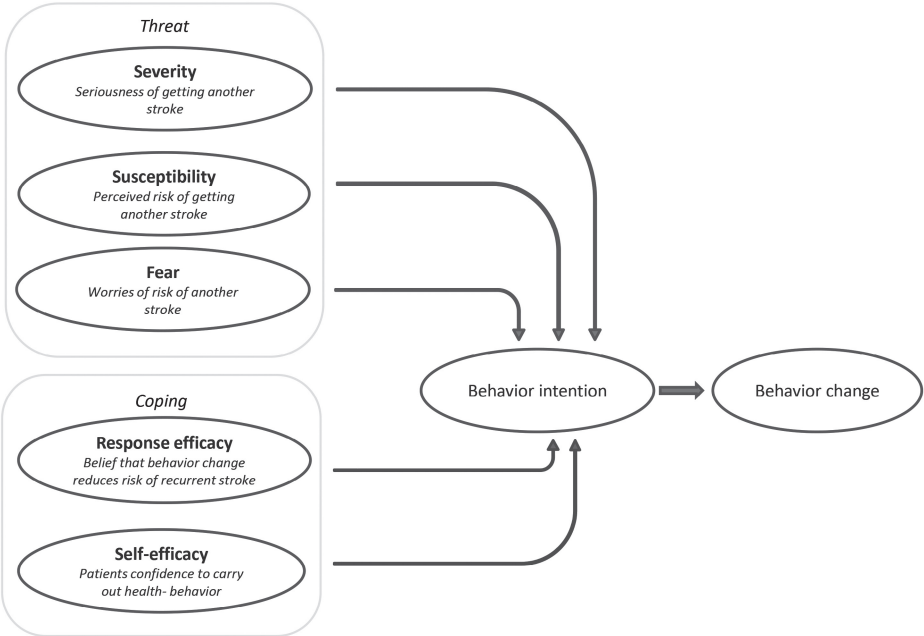
### **Health-related behavior change after stroke**

Stroke is the third cause of death and the leading cause of disability in developed countries.<sup>[1]</sup> The incidence of stroke rises with increasing age and is expected to increase further the next years.<sup>[2]</sup> After a TIA or ischemic stroke patients have an increased risk of recurrent stroke and other cardiovascular events.<sup>[3, 4]</sup> Risk factors for recurrent cardiovascular events can be classified into three major groups: non-modifiable risk factors such as age, sex, ethnicity, and family history; medically modifiable risk factors including hypertension, hyperlipidemia, and diabetes and behaviorally modifiable risk factors like cigarette smoking, physical activity and diet.<sup>[5]</sup> In patients with coronary artery disease, the benefits of lifestyle management on vascular risk factors as well as the risk of vascular death and myocardial infarction have been demonstrated.<sup>[6-8]</sup> However, the majority of these patients failed to sustain health-related behavior change in the long-term. Supporting patients in changing health-related behavior after TIA or stroke may be an effective way to reduce stroke recurrence and is recommended in many guidelines.<sup>[9-11]</sup>

### **Models for behavior change**

The process of behavior change is complex and has been described in several models. I used two of these models in my thesis. The first is Roger’s revised Protection Motivation Theory (PMT) <sup>[12]</sup> that describes socio-cognitive factors that play a role in individuals’ motivation to change or not to change their health-related behavior (Fig. 1). The PMT has shown to be an useful model for predicting health-protective intentions and behavior changes in

other conditions, such as diabetes, coronary heart disease, and breast cancer.<sup>[13]</sup> Similar to other models this theory assumes that behavior change is a consequence of behavioral intention to change. An intention to change only develops when a threat is perceived and a coping response is available. We have added fear to this model, because fear is often present after TIA or ischemic stroke and may influence health-related behavior as well.<sup>[14, 15]</sup>



**Figure 1.** Potential determinants of health-related behavioral intention to change and actual change in patients with TIA or ischemic stroke based on the Protection Motivation Theory with fear added

Besides the Protection Motivation Theory I used the Social-Cognitive Theory. This theory also describes how cognitive, behavioral, personal and environmental factors affect behavior and motivation.<sup>[16, 17]</sup> One of the factors that play a central role in this process is perceived self-efficacy, i.e. a person’s confidence to carry out behavior necessary to reach a desired goal. As self-efficacy is an important precondition for successful self-management to change health-related behavior,<sup>[18, 19]</sup> we used this model to study the role of self-efficacy in the behavior change process after TIA or ischemic stroke. When aiming to support patients after a TIA or ischemic stroke by means of an intervention these models for behavior change have to form the basis.<sup>[20-22]</sup>

## **Interventions for health-related behavior change**

At present, only limited and inconsistent data are available on interventions to support patients in health-related behavior change after TIA or ischemic stroke<sup>[23,24]</sup>. The existing interventions vary from personal education, exercise or lifestyle classes, to motivational counseling (not specified), telephone support, home visits and interviews.<sup>[25]</sup> The heterogeneity in the applied interventions with regard to content, intensity, type of behavior and duration makes it difficult to compare these studies.<sup>[23]</sup> Furthermore, follow-up rates are often short and patients often have physical barriers such as fatigue or pain, lack of knowledge, absent or inadequate social support, and cognitive problems which may also affect behavior.<sup>[26-30]</sup> One of the conclusions based on present knowledge is that the majority of people with cardiovascular disease fail to sustain lifestyle modification in the long-term.<sup>[31,32]</sup>

## **Aims and outline of the thesis**

The aim of my thesis was to study health-related behavior change after TIA or ischemic stroke. It consists of two parts. The first step towards developing a successful intervention is to unravel factors that play a role in the behavior change process after TIA or ischemic stroke. This provides insight into the mechanism of behavioral change in this group and thereby direction on components that the intervention should contain. Therefore, Part 1 of my research focuses on determinants of lifestyle behavior change after TIA or stroke. To gain insight in the process of lifestyle behavior change, we assessed determinants of intention to change health-related behavior and actual change based on the Protection Motivation Theory. I describe this study in Chapter 1.1. In this quantitative study, we were unable to examine patients' subjective perspective of health behavior. We therefore performed a qualitative study with in-depth, semi-structured interviews of patients' personal experience and view on health behavior change after TIA or ischemic stroke. This study is described in Chapter 1.2. As self-efficacy may play an important role in health-related behavior change, Chapter 1.3 focuses on self-efficacy for health-related behavior change. This part ends with Chapter 1.4 in which I describe the determinants of intention to change health-related behavior over time in order to examine the optimal timing of an intervention to support patients in behavior change. Part 2 focuses on studies supporting patients in health-related behavior change. In Chapter 2.1 I review health education in patients with a TIA or ischemic stroke patients and the effects aiming at feasibility, effectiveness at the level of knowledge, attitude and skills, health behavior changes and stroke outcome. After the assessment of determinants of health-related behavior change, we developed an intervention that we subsequently studied in a randomized clinical trial. Whether motivational interviewing is an effective intervention in supporting patients in health-related behavior change is described in Chapter 2.2. In Chapter 3 and 4, I present a general discussion and a summary of the results presented in this thesis.

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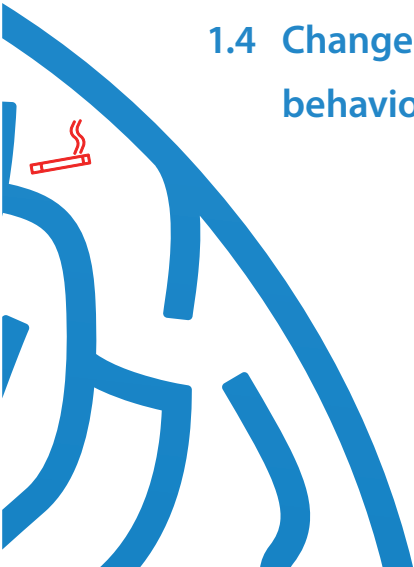
# PART

# 1



# Determinants of health-related behavior change after TIA or ischemic stroke

- 1.1 Determinants of intention to change health-related behavior and actual change in patients with TIA or minor ischemic stroke
- 1.2 Patients perspectives of health-related behavior change after TIA or minor ischemic stroke
- 1.3 Self-efficacy and its determinants for health-related behavior change in patients with TIA or minor ischemic stroke
- 1.4 Changes in determinants of health-related behavior after TIA or ischemic stroke over time



# Chapter

# 1.1



# Determinants of intention to change health-related behavior and actual change in patients with TIA or minor ischemic stroke

D. Brouwer-Goossensen

L. van Genugten

H. Lingsma

D.W.J. Dippel

P.J. Koudstaal

M.H. den Hertog



## ABSTRACT

**Objective:** To assess determinants of intention to change health-related behavior and actual change in patients with TIA or ischemic stroke.

**Methods:** In this prospective cohort study, 100 patients with TIA or minor ischemic stroke completed questionnaires on behavioral intention and sociocognitive factors including perception of severity, susceptibility, fear, response-efficacy and self-efficacy at baseline. Questionnaires on physical activity, diet and smoking were completed at baseline and at 3 months. Associations between sociocognitive factors and behavioral intention and actual change were studied with multivariable linear and logistic regression.

**Results:** Self-efficacy, response efficacy, and fear were independently associated with behavioral intention, with self-efficacy as the strongest determinant of intention to increase physical activity (aBeta 0.40; 95% CI 0.12-0.71), adapt a healthy diet (aBeta 0.49; 95% CI 0.23-0.75), and quit smoking (aBeta 0.51; 95% CI 0.13-0.88). Intention to change tended to be associated with actual health-related behavior change.

**Conclusion:** Self-efficacy, fear, and response-efficacy were determinants of intention to change health-related behavior after TIA or ischemic stroke.

**Practice implications:** These determinants of intention to change health-related behavior after TIA or ischemic stroke should be taken into account in the development of future interventions promoting health-related behavior change in these group of patients.

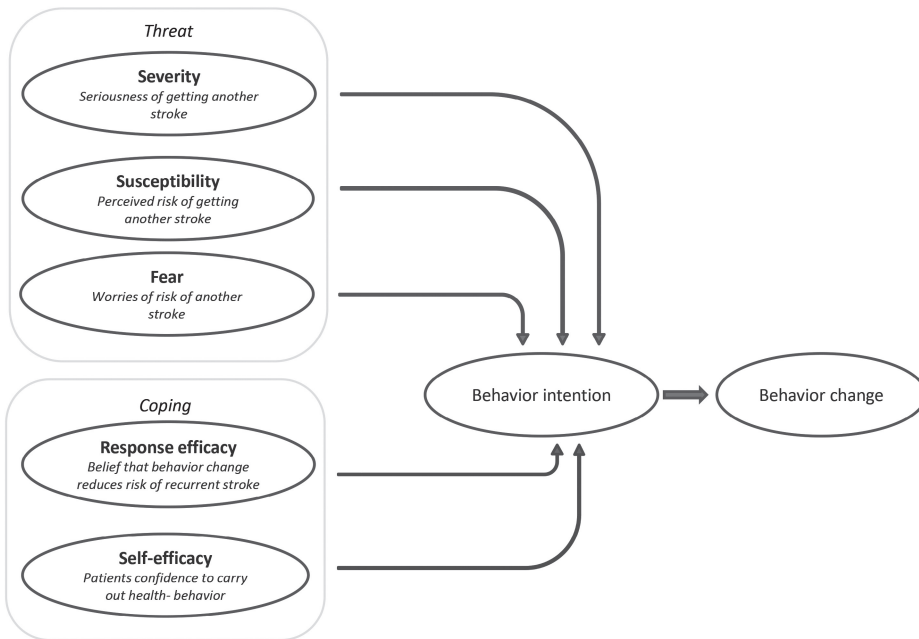
*Published in Patient Education and Counseling, Nov 2015*

## Background

In contrast to the established effectiveness of pharmacological and surgical treatment for prevention of ischemic stroke recurrence, little is known about the importance of change in health-related behavior after TIA or ischemic stroke. The strong epidemiological association between health-related behaviors, such as physical inactivity, smoking, and unhealthy diet and the incidence of stroke, and their adverse impact on other vascular conditions suggest that it is reasonable to extrapolate the results from primary prevention studies to secondary prevention after TIA or ischemic stroke.<sup>[1-13]</sup> Moreover, healthy lifestyle is known to improve vascular risk factors, for instance, modest weight loss in the obese can improve control of hypertension and hyperglycemia. Hence, interventions promoting healthy behavior may be an effective way to reduce stroke recurrence.

Only limited and inconsistent data are available on the effect of lifestyle modification on both traditional vascular and lifestyle risk factors for recurrent stroke, and there are no large randomized controlled trials on lifestyle modification and prevention of stroke recurrence.<sup>[14-18]</sup> In patients with coronary artery disease, the benefits of lifestyle management on vascular risk factors as well as the risk of vascular death and myocardial infarction have been demonstrated.<sup>[19-21]</sup> However, these results can probably not be directly extrapolated to patients with TIA or ischemic stroke as these patients are generally older, and often experience cognitive and functional impairments, which may influence their health-related behavior.

Various disease-related and sociocognitive factors might influence health-related behavior. Roger's revised Protection Motivation Theory (PMT)<sup>[22]</sup> describes sociocognitive factors that play a role in individual's motivation to change or not to change health-related behavior (Figure 1). Similar to other models including the Health Belief Model, Theory of Planned Behavior and the transtheoretical model, this theory assumes that behavior change is a consequence of behavioral intention to change.<sup>[23]</sup> An intention to change only develops when a threat is perceived and a coping response is available.



**Figure 1.** Potential determinants of health-related behavioral intention to change and actual change in patients with TIA or ischemic stroke based on the Protection Motivation Theory with fear added

The Protection Motivation Theory has shown to be an useful model for predicting health-protective intentions and behavior changes in other conditions, such as diabetes, coronary heart disease, and breast cancer.<sup>[24]</sup> We have added fear to this model, because fear is often present after TIA or ischemic stroke and may influence health-related behavior as well.<sup>[25, 26]</sup> At present, it is unclear if and how the Protection Motivation Theory factors determine the intention to change and actual change in health-related behavior in patients with TIA or ischemic stroke. Insight into determinants of intentions and changes in health-related behavior may be necessary to develop successful health promoting interventions in patients with TIA or ischemic stroke.

Therefore, in this study, we aimed to assess determinants of health-related intention to change and actual behavior change in patients with recent TIA or ischemic stroke.



## Methods

We conducted a prospective cohort study. Patients were eligible for inclusion if they were 18 years or older and had a clinical diagnosis of TIA, including amaurosis fugax, or minor ischemic stroke and a modified Rankin Scale score of 3 or less. The modified Rankin Scale (mRS) is a commonly used scale for measuring the degree of disability or dependence in the daily activities of people who have suffered a stroke. Scores on the mRS range from 0 (no symptoms at all) to 5 (severe disability); for statistical purposes, death has a score of 6.<sup>[27]</sup>

Patients were excluded if they were discharged to a nursing home, were not Dutch-speaking or had severe aphasia. Patients were recruited in the first week after admission to the stroke unit or TIA outpatient clinic. All patients received routine general lifestyle advice including regular physical exercise, healthy diet, and advice against smoking as part of standard care at baseline.

At baseline, we recorded data on clinical features of TIA or ischemic stroke, quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS)<sup>[28]</sup>, demographic data, vascular risk factors and history, and use of medication.

Patients were assessed at enrollment, and at 3 months thereafter. The initial assessment included self-reported questionnaires on sociocognitive determinants. Furthermore, all patients underwent a cognitive assessment. The questionnaires include the following:

- Severity, assessed with a single item: 'Getting another stroke would be a very bad thing to happen to me', scored on a scale ranging from 1 (definitely not) to 5 (definitely yes).
- Susceptibility, assessed with a 5-point scale ranging from definitely will not (0) to definitely will (5) get another stroke.<sup>[29]</sup>
- Fear, measured with 8 questions. Patients were asked on a scale of 1 to 5 how nervous they are when thinking of getting another stroke, how upset they get, depressed or jittery, if their heart beats faster, and if they feel uneasy or anxious.<sup>[30]</sup>
- Response-efficacy, assessed with the following statement: 'For me, regular physical activity will reduce my chances of getting another stroke' (1 = strongly disagree; 5 = strongly agree). Similar questions were asked for dietary change and smoking cessation.<sup>[29,30]</sup>

- Self-efficacy, measured with the self-efficacy scale, a 9-item scale with scores that range from 1 to 5. Higher values indicate more confidence to carry out the behavior necessary to reach the desired goal.<sup>[30-32]</sup> Questions are formulated as: I think I am able to quit smoking / choose healthy food/ care for enough physical activity. Total scores range from 5-35.
- Depression as measured with the CES-D (Centre for Epidemiologic Studies Depression Scale) for both depression and anxiety.<sup>[33, 34]</sup> Higher scores indicate more depressive symptoms.
- Cognitive impairment, assessed with Montreal Cognitive Assessment (MoCA), a rapid screening instrument for cognitive impairment, in particular in stroke patients.<sup>[35]</sup>

The MoCa screens visuospatial/ executive functions, naming, memory, attention, language, abstraction and delayed recall and orientation. Scores range from 0-30.

### Outcome measures

Primary outcome measures were intention to change physical activity, dietary behavior, and smoking cessation at baseline and actual change in these behaviors at 3 months.

The main outcome, behavioral intention (intention to change) was assessed by means of a single item.<sup>[29]</sup> Patients were asked 'on a scale of 1 to 5, how likely is it: - to get 30 minutes of moderate to heavy daily physical activity in the next 3 months - to decrease your intake of unhealthy fats/ reduce their total energy intake in the next three months? - to stop smoking within the next 3 months?'

At baseline and 3 months thereafter, health-related behavior was assessed:

- Physical activity, measured with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire. Patients were asked to report activities performed for at least 10 minutes during the last 7 days, and time spent in physical activity performed across leisure time, work, domestic activities, and transport at each of 3 intensities: walking, moderate, and vigorous.<sup>[29]</sup> We used reported minutes of moderate and vigorous physical activity to calculate a total physical activity score of minutes a day.
- Dietary behavior, evaluated with the short Food Frequency Questionnaire (FFQ). This 14-item scale assesses the intake of saturated fatty acids, unsaturated fatty acids, and fruits and vegetables over the week before the visit. An overall cardiovascular dietary

score was calculated, ranging from -17 to +19, the higher the score, the more favorable the dietary pattern.<sup>[36]</sup>

- Actual smoking status was assessed with questions on current smoking status, how many years they have smoked and how much cigarettes a patient smokes a day. Smoking was defined as current smoking.

Furthermore, body mass index (BMI), and waist circumference were measured at baseline and 3 months thereafter.

**Table 1:** Baseline characteristics ( N=100)

Sex (male), n (%)	60 (60)
Age (years), mean (SD)	64 (12)
<i>Event characteristics:</i>	
Event type (TIA), n (%)	53 (53)
Stroke etiology (TOAST) <sup>1</sup> , n (%)	
Large vessel disease	13 (13)
Cardiac embolism	15 (15)
Small vessel disease	19 (19)
Other	0
Undetermined	53 (53)
NIHSS score <sup>2</sup> , median (IQ)	3 (1-5)
<i>Vascular history, n (%)</i>	
TIA	18 (18)
Ischemic stroke	15 (15)
Ischemic heart disease	36 (36)
Atrial fibrillation	11 (11)
Peripheral arterial disease	8 (8)
No vascular history	49 (49)
<i>Cognition and depression:</i>	
Score on MoCA <sup>3</sup> , median (IQ) scores from 0-30	24 (21-26)
Score on CES-D <sup>4</sup> , median (IQ) scores from 0-30	7 (5-13)
<i>Vascular risk factors:</i>	
Hypertension, n (%)	65 (65)

**Table 1:** Baseline characteristics ( N=100)

Systolic blood pressure (mmHg), mean (SD)	135 (22)
Diastolic blood pressure (mmHg), mean (SD)	78 (13)
Hypercholesterolemia, n (%)	79 (79)
LDL level (mmol/l), mean (SD)	3.17 (1.0)
<i>Lifestyle:</i>	
Smoking, n(%)	36 (36)
Alcohol abuse, n (%)	5 (5.2)
Physical exercise <sup>5</sup> (min/day), median (IQ)	129.6 (60-218.6)
Physical exercise > 30 min a day n (%)	75 (77)
Overall dietscore <sup>6</sup> , median (IQ) scores from -17 to +19	1.0 (-2-2.5)
BMI (kg/m <sup>2</sup> ), mean (SD)	26,5 (3.6)
Overweight (BMI>25), n(%)	64 (64)
<i>Threat:</i>	
Severity <sup>7</sup> , median (IQ) scores from 0-4	4 (3-4)
Susceptibility <sup>8</sup> , median (IQ) scores from 0-4	2 (1-3)
Fear <sup>9</sup> , median (IQ) scores from 0-32	16 (7-21)
<i>Coping:</i>	
Response efficacy <sup>10</sup> non smokers, median (IQ) scores from 0-8	8 (6-8)
Response efficacy smokers, median (IQ) scores from 0-12	10 (9-12)
Self-efficacy <sup>11</sup> non smokers, total median (IQ) from 5-30	26 (23-28,5)
Self-efficacy smokers total, median (IQ) from 5-35	30 (27.5-33)

<sup>1</sup> Classification of subtype of acute ischemic stroke developed for the Trial of Org 10172 in Acute Stroke Treatment (TOAST).

<sup>2</sup> Quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS), a 15-item scale with scores that range from 0 to 42 and higher values indicating greater severity.

<sup>3</sup> Assessed with the Minimal Mental State Examination and Montreal Cognitive assessment (MoCA).

<sup>4</sup> Scored with the Centre for Epidemiologic Studies Depression Scale (CES-D).

<sup>5</sup> Measured with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire.

<sup>6</sup> Evaluated with the short Food Frequency Questionnaire (FFQ). The higher the score, the more favorable the dietary pattern.

<sup>7</sup> Severity, assessed with a single item: 'Getting another stroke would be a very bad thing to happen to me'. The item will be scored on a scale ranging from 1 (definitely not) to 5 (definitely yes).

<sup>8</sup> Susceptibility, assessed with a 5-point scale ranging from definitely will not (0) to definitely will (5) get another stroke.

<sup>9</sup> Fear measured with 8 questions, asking on a scale of 1-5 how nervous patients are when thinking of getting another stroke, how upset they get, depressed or jittery, if their heart beats faster, they feel uneasy or anxious.

<sup>10</sup> Response efficacy. Patients will be asked to rate their level of agreement (1 = strongly disagree; 5 = strongly agree) with the following statement: 'For me, regular physical activity will reduce my chances of getting another stroke'. Similar questions will be asked for dietary change and smoking cessation.

<sup>11</sup> Self-efficacy, measured with the self-efficacy scale, a 9-item scale with scores that range from 1 to 5. Higher values indicate more confidence to carry out the behavior necessary to reach the desired goal.

## Statistical analysis

Statistical analysis were performed with STATA 12.1 statistical package (Statacorp, College Station, Texas). Missing variables of IPAQ-S and FFQ questionnaire were imputed with single imputation. We studied the relation between baseline intention to change and actual health-related behavior change after three months with univariable linear and logistic regression. Second, univariable linear regression analyses were performed to identify sociocognitive determinants of behavioral intention at baseline. The analyses were also conducted for actual change after three months. Determinants with  $p$ -value  $\leq 0.2$  were further analyzed in multivariable models. Adjustments were made for age, sex, cognitive performance, depression and event type (TIA versus ischemic stroke). Interactions between age, sex, depression, cognitive performance and event type (TIA versus ischemic stroke) on the one hand and sociocognitive determinants on the other were explored as well.

## Results

We included 100 patients between February and October 2012. Mean age was 64 years (SD 12), 60% of the patients were male and 53% had a TIA (Table 1). Follow up was completed in 87 patients: 5 patients refused follow-up, 1 patient was lost to follow-up, 1 patient was excluded because of severe other comorbidity, 1 because of intracerebral hematoma during follow-up, 2 patients because of misdiagnosis, and 3 patients were discharged to another hospital. No significant differences in baseline characteristics were found between included patients and excluded patients (data not shown). Food frequency questionnaire was completed in 62 patients and the physical activity questionnaire IPAQ-S in 70 patients.

Median behavioral intention to change was 2 (IQ 2-4) for physical activity, and 1 (IQ 0-1) for dietary behavior and smoking cessation. Thirty-two patients (37%) changed their health-related behavior by improving more than 30 minutes in physical activity a day and 9 patients (31%) stopped smoking. Only one patient (2%) improved in dietary behavior. Forty-four patients (53%) lost weight, on average 1.21 kg (SD 3.43). No changes in waist circumference were found.

We found that intention to change was not significantly associated with actual change. However, patients with a higher intention to change tended to change their health-related behavior more often (Table 2). No associations between sociocognitive factors and actual change were found (data not shown).

**Table 2:** The association of intention to change and actual change in health related behavior after TIA or ischemic stroke

	OR (95% CI)	aOR (95% CI) <sup>1</sup>	
Quit smoking	1.21 (0.62-2.34)	1.15 (0.60-2.24)	
	Beta (95% CI)	aBeta (95% CI) <sup>1</sup>	R squared
Improved physical activity (min/day) <sup>2</sup>	15.75 (-16.62-48.12)	17.35 (-15.79-50.49)	0.20
Dietary change	-0.15 (-0.74-0.45)	-0.16 (-0.75-0.43)	0.21

<sup>1</sup> adjusted for age and sex, <sup>2</sup> measured with IPAQ-S, <sup>3</sup> measured with FFQ questionnaire

Baseline self-efficacy, severity, response-efficacy and fear were selected as potential determinants of intention to change health-related behavior based on the univariable regression analysis (Table 2). Self-efficacy, fear and response efficacy were independently associated with intention to change health-related behavior in multivariable regression analysis (Table 3). After adjustment for age, sex, event type, score on CES-D, and score on the MoCA, self-efficacy was the strongest determinant of intention to change physical activity (aBeta 0.40; 95% CI 0.12-0.71), diet (aBeta 0.49; 95% CI 0.23-0.75) and smoking (aBeta 0.51; 95% CI 0.13-0.88). We found no interactions between age, sex, depression, cognitive performance and event type on the one hand and sociocognitive factors on the other (data not shown).

**Table 3:** Univariable and multivariable relations between sociocognitive determinants and intention to change health related behavior

## a. Intention to change physical activity

	Beta	p	aBeta <sup>1</sup>	aBeta <sup>2</sup>
Total self-efficacy	0.42 (-0.02-0.87)	0.06		
Self-efficacy	0.39 (0.13-0.66)	0.00	0.31 (0.03-0.59)	0.35 (0.03-0.67)
Fear	0.02 (-0.02-0.05)	0.29		
Severity	0.32 (0.00-0.65)	0.05	0.13 (-0.20-0.47)	
Susceptibility	0.11 (-0.15-0.37)	0.41		
Response-efficacy	0.26 (-0.03-0.54)	0.08	0.20 (-0.09-0.49)	0.34 (-0.00-0.69)

<sup>1</sup> multivariable regression analysis, <sup>2</sup> adjusted for age, sex, event type, score on CES-D and score on MoCA

## b. Intention to change diet

	Beta	p	aBeta <sup>1</sup>	aBeta <sup>2</sup>
Total Self-efficacy	0.34 (-0.11-0.79)	0.14		
Self-efficacy at home	0.18 (-0.17-0.53)	0.31		
Self-efficacy when not at home	0.30 (0.04-0.55)	0.02	0.38 ( 0.13-0.63)	0.56 (0.23-0.89)
Fear	0.04 (0.00-0.07)	0.01	0.04 (-0.00-0.07)	0.03 (-0.02-0.08).
Severity	0.41 (0.19-0.72)	0.01	0.09 (-0.24-0.42)	
Susceptibility	-0.17 (-0.42-0.09)	0.19		
Response-efficacy	0.42 (0.12-0.72)	0.01	0.42 ( 0.13-0.71)	0.29 (-0.17-0.75)

## c. Intention to stop smoking

	OR	p	aBeta	aBeta <sup>2</sup>
Total self-efficacy	0.37 (-0.36-1.07)	0.30		
Self-efficacy	0.63 (0.34-0.92)	0.00	0.48 (0.21-0.75)	0.39 (-0.28-1.06)
Fear	0.05 (0.01-0.09)	0.02	0.04 (-0.01-0.07)	
Severity	0.37 (-0.07-0.81)	0.10		
Susceptibility	-0.12 (-0.50-0.26)	0.53		
Response-efficacy	0.75 (0.31-1.19)	0.00	0.46 (0.09-0.84)	0.52 (-0.26-1.30)

<sup>1</sup> multivariable regression analysis, <sup>2</sup> adjusted for age, sex, event type, CES-D and score on MoCA

## Discussion

In this prospective study, we assessed determinants of intention to change health-related behavior and actual change based on the Protection Motivation Theory in stroke patients. We showed that self-efficacy, response-efficacy, and fear were independently associated with intention to change health-related behavior, with self-efficacy as the strongest determinant. Furthermore, we found a trend to increased health-related behavior change in patients with higher intention to change.

The Protection Motivation Theory has shown to be an useful model for predicting health-protective intentions and behavior changes in diabetes, coronary heart disease, and cancer.<sup>[24, 37]</sup> The application of the protection motivation theory in physical activity has been tested in several studies. It shows early evidence for the effectiveness of the Protection Motivation Theory as a theoretical framework for guiding the development of physical activity interventions among healthy populations.<sup>[38, 39]</sup> In studies with patients with myocardial infarction and diabetes, the protection motivation theory has shown to be useful to explain physical activity.<sup>[29, 40-43]</sup> One study found an association between

high fear and intention to increase physical activity after 6 months.<sup>[29]</sup> Response efficacy was associated with intention to change health behavior in persons at risk of stroke and predicted increase in physical activity in two studies with cardiac patients.<sup>[42-44]</sup> Similar to our findings intention to change was the key predictor for health-related behavior change in myocardial infarction.<sup>[40]</sup> In all these studies, self-efficacy appeared to be an important precondition for intention and actual health-behavior change. Self-efficacy has also been identified as the most common and most reliable predictor of exercise in the quantitative literature in a review focusing on psychological factors in uptake and maintenance of physical activity after stroke.<sup>[45]</sup> The Protection Motivation Theory has also been studied in relation to dietary behavior in patients with coronary artery disease or myocardial infarction in four studies.<sup>[29, 40, 42, 43]</sup> In line with our study, these four studies found that self-efficacy was an important determinant of behavior intention. In one study fear had an inverse effect on intention to adapt a healthy diet at six months in contrast to our study.<sup>[29]</sup>

To the best of our knowledge, this is the first study that focuses on the determinants of intention to change and actual change in health-related behavior after TIA or ischemic stroke with the Protection Motivation Theory. A few studies explored determinants of health-related behavior in stroke patients based on the Health Belief Model<sup>[45]</sup>. One study with 42 patients with TIA or stroke showed that stroke seriousness and severity were the most predictive beliefs of behavior change. However, these beliefs were not independently associated with health-related behavior change<sup>[46]</sup>.

Strengths of our study are that we collected detailed information on potential determinants of intention to change health-related behavior and patient characteristics. Also, this is one of the few studies that focuses on the determinants of actual change in health-related behavior after TIA and ischemic stroke. Our study also has some limitations. First, it was not designed to change health-related behavior, and as a result only a few patients changed their health-related behavior. Therefore, we were not able to assess determinants of actual health-related change. This might partly explain why we only found a trend towards increased health-related behavior in patients with higher intention to change. However, previous studies have shown a gap between intention and actual change in health-related behavior as well.<sup>[47]</sup> In our study, intention to change predicted 20% of physical activity and dietary behavior change, comparable with previous studies. In a post intentional phase, various factors can compromise or facilitate the translation of intentions into actions. Some of these factors have been identified, such as maintenance of self-efficacy and recovery of self-efficacy as well as action planning and coping planning<sup>[48]</sup>. Nevertheless much of the behavioral change processes are still unknown.



The lack of spontaneous health-related behavior change in our study stresses the importance of an intervention supporting this behavior change after TIA or ischemic stroke. A second limitation is that only 87% of our patients completed the follow-up, and IPAQ-S and Food frequency questionnaire were not completed in all patients, probably because of the length and difficulty of these questionnaires. However, comparison of the excluded patients with the study population showed no significant differences with regard to age, sex, cognitive and functional impairment. Finally, all questions on behavioral intention, sociocognitive determinants and health-related behavior are filled in by patients themselves. Therefore, the answers might be socially approved.

The determinants of intention to change health-related behavior were mainly coping factors. Self-efficacy was the strongest determinant of intention to stop smoking, increase physical activity and improve healthy diet. Self-efficacy appeared a convincing and powerful predictor of intentions in other cardiovascular studies.<sup>[49-51]</sup> It has also been found to have a direct effect on health-related behavior and is the strongest predictor of health-related behavior change.<sup>[51, 52]</sup> Self-efficacy can be developed by mastery experiences (successes build a robust belief in one's personal efficacy), vicarious models (rolemodels), social persuasion (social support) and psychological and emotional arousal.<sup>[53]</sup> Interventions which aim to improve self-efficacy should be based on these factors. There is growing evidence that self-management approaches are effective in increasing self-efficacy<sup>[54]</sup>. As far as we know only a few studies focused on improving self-efficacy or self-management in patients with TIA or ischemic stroke<sup>[55-58]</sup>, but we found only one study which focused on self-efficacy for health behavior change.<sup>[59]</sup> Motivational interviewing can be used to help patients exercise more, lose weight, reduce problematic substance use and boost self-efficacy in their ability to make health-related behavior changes. Therefore it might be a promising method and can be incorporated in future self-management programs or other health-related behavior change interventions.<sup>[60]</sup>

Response efficacy may be an important determinant as behavior change is hard to accomplish and patients are only willing to change when they believe that making the change is effective in reducing the risk of another events. Fear was the only perceived threat factor that influenced intention to change. As far as we know, fear has not been studied in relation to intention to change health-related behavior in patients with TIA or stroke before. Fear can be a strong influencing and uncontrollable factor, which can lead to the intention to change. Otherwise fear can work counterproductive, as it can lead to avoidance or lead to denial based forms of coping. Earlier research showed that fear may be a motivator for action, but is insufficient to have this effect on its own. A meta-analysis has shown a significant interaction between threat (fear) and efficacy, such that threat only had a motivating effect when high efficacy is present.<sup>[61]</sup>

## Conclusion

In conclusion, we found that self-efficacy, response-efficacy, and fear were determinants of intention to change health-related behavior after TIA or ischemic stroke, with self-efficacy as the strongest predictor.

## Practice implications

At present, little is known about promoting health-related behavior change after TIA or ischemic stroke. Our study provides insight in determinants that may influence intention to change health-related behavior. Future studies should focus on factors that explain the gap between intention to change and actual change in health-related behavior and should focus on interventions that have the ability to influence these determinants. In daily practice, the determinants of intention to change health-related behavior in patients with TIA or ischemic stroke should be taken into account by physicians promoting health-related behavior change in these group of patients.

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# Chapter

# 1.2





# Patient perspectives on health-related behavior change after TIA or ischemic stroke

D. Brouwer-Goossensen

H.M. den Hertog

M.A. Mastebroek-de Jong

L.J.E.W.C. van Gemert-Pijnen

E. Taal



## ABSTRACT

**Objective:** We aimed to explore patients' perspectives on health-related behavior change, support in this change and sustaining healthy behavior.

**Methods:** We conducted a descriptive qualitative study with in-depth, semi-structured interviews in eighteen patients with recent TIA or ischemic stroke. Interviews addressed barriers, facilitators, knowledge and support of health-related behavior change framed by the Protection Motivation Theory and Transtheoretical Model. All interviews were transcribed and thematically analyzed.

**Results:** Patients understand what constitutes a healthy lifestyle, but seem unable to adequately appraise their own health-related behavior. More than half of the patients were satisfied with their lifestyle and felt no urgency to change. Self-efficacy was the most important determinant for health-related behavior change and mentioned both as barrier and facilitator. Most of the patients did not need support or already received support in changing health behavior. Patients indicated knowledge, guidelines and social support as most needed to support behavior change and preserve a healthy lifestyle.

**Conclusion:** This study suggests that patients with recent TIA or ischemic stroke do not have a proactive approach towards health-related behavior change.

**Practice implications:** Increasing knowledge on lifestyle risk factors for ischemic stroke and improving self-efficacy may be important targets for lifestyle interventions after ischemic stroke.

*Submitted*

## Background

Stroke is the third cause of death and the first cause of disability in developed countries<sup>[1]</sup>. The incidence of stroke rises with increasing age and is expected to increase further the next years<sup>[2]</sup>. Transient Ischemic Attacks (TIA's) can be seen as a warning sign and require urgent evaluation to prevent a stroke.<sup>[3]</sup> As recurrence rates are high<sup>[4]</sup>, risk factor and health behavior management is of great importance. Interventions promoting a healthy lifestyle after TIA or ischemic stroke may be an effective way to reduce stroke recurrence and are strongly recommended in many guidelines.<sup>[5-7]</sup> Recommended lifestyle behaviors to prevent recurrence after TIA or ischemic stroke includes regular physical exercise (more than 30 minutes of moderate or intense activity a day), healthy diet, stop smoking and no excessive use of alcohol. However, at present, only limited and inconsistent data are available on interventions to support patients in health-related behavior change after TIA or ischemic stroke.<sup>[8-13]</sup>

Health-related lifestyle change after ischemic stroke and TIA is difficult to carry out successfully and the majority of people fail to sustain lifestyle modification in the long-term.<sup>[14, 15]</sup> Patients' knowledge about risk factors for ischemic stroke or TIA is often poor<sup>[16]</sup> and even when patients believe that their lifestyle is related to their stroke, they did not change their smoking or excessive alcohol drinking habits.<sup>[17]</sup> Patients experience physical barriers such as pain, fatigue balance problems or fear of falling. Reported mental barriers include lack of motivation or social support and boredom which contributed to persistent smoking. Also environmental barriers like bad weather, bad roads and costs of healthy foods were experienced as barriers for behavior change.<sup>[18]</sup>

The process of behavior change is complex and has been described in several models. Roger's revised Protection Motivation Theory (PMT)<sup>[19]</sup> describes cognitive factors that play a role in individual's motivation to change or not to change health-related behavior. Similar to other models including the Health Belief Model, Theory of Planned Behavior and the Transtheoretical Model, this theory assumes that behavior change is a consequence of behavioral intention to change. An intention to change only develops when a threat is perceived and a coping response is available. We showed that fear of recurrence, self-efficacy (patients confidence to carry out lifestyle behavior) and response efficacy (believe that lifestyle behavior change reduces risk of recurrent ischemic stroke) are determinants of intention to change health behavior after TIA or ischemic stroke.<sup>[20]</sup> Understanding of patients' perspectives of these determinants of health-related behavior change after TIA or ischemic stroke can facilitate the development of successful behavior change strategies.

At present, it is unclear how patients judge their own lifestyle after TIA or ischemic stroke, which facilitating factors and barriers for health-related behavior change are experienced, and which support patients desire to support health-related behavior change. Hence, we explored patients' perspectives on health-related behavior change and support in health-related behavior change after TIA or minor ischemic stroke in a qualitative study with in-depth, semi-structured interviews.

## Methods

We conducted a descriptive qualitative study with in-depth, semi-structured interviews. Patients were eligible for inclusion if they were 18 years or older and had a clinical diagnosis of TIA or minor ischemic stroke and a modified Rankin Scale score of 3 or less. The modified Rankin Scale (mRS) is a commonly used scale for measuring the degree of disability or dependence in the daily activities of people who have suffered a stroke. Scores on the mRS range from 0 (no symptoms at all) to 5 (severe disability).<sup>[21]</sup> Patients were recruited in the first week after admission to the stroke unit. Eighteen patients with TIA or ischemic stroke were interviewed. All patients received verbal routine general lifestyle advice including regular physical exercise, healthy diet, and advice to stop smoking as part of standard care of the neurologist. We recorded data on quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS)<sup>[22]</sup>, demographic data, education and BMI.

## Interviews

All 18 patients underwent an in-depth interviews of 60 minutes taken by MdJ. Seventeen patients were interviewed at home and one in the hospital. Interviews were audiotaped, transcribed and thematically analyzed by MdJ and DBG. Interviews followed a scheme that addressed patients' assessment of their own lifestyle, barriers and facilitators of health-related behavior change framed by the Protection Motivation Theory and desired support in the behavior change process (Table 1). Patients were asked to describe a healthy lifestyle and to compare it with their own lifestyle. After that patients were asked if they had changed their lifestyle after the TIA or ischemic stroke and which barriers and facilitating factors they experienced. Questions were asked about the lifestyle factors of smoking, exercise, (healthy) diet and alcohol consumption, and the motivation to change or not to change the lifestyle. Finally, they were asked what type of support they need when changing their lifestyle and what could help to maintain a healthy lifestyle.

**Table 1. Interview guide**

1.	What was the cause of your stroke/TIA?
2.	How would you describe a healthy lifestyle?
3.	How would you describe your lifestyle?
4.	Did your lifestyle change after your stroke/TIA?
5.	Did you change your lifestyle before?
6.	Did you receive advice about a healthy lifestyle in the hospital?
7.	Are you planning to follow this advice and if so,
8.	How are you planning to follow this advice?
9.	Which support would you like in changing your lifestyle after stroke or TIA?
10.	Which support would you like in maintaining a healthy lifestyle?

### *Qualitative analysis*

All interviews were analyzed with open, axial and selective coding using a framework approach<sup>[23]</sup> by the interviewer (MdJ) and researchers (DBG and ET). In first stage MdJ listened the interview recordings while reading the transcripts. In the second stage MdJ divided interviews into fragments which were classified over the determinants of the Protection Motivation Theory. No qualitative software was used. In the third stage DBG and ET reviewed this classification. Interviews were read again and fragments further refined. Barriers and facilitators per factors were selected by MdJ and reviewed by DBG and ET.

### **Results**

Of the eighteen interviewed patients the mean age was 65 years (IQR 48-80), 11 (61%) were male and 14 (78%) had a TIA (Table 1). Most patients had a mRS of 0 or 1, which means that they were mildly or not disabled. None of the patients used more alcohol than advised and 3 (17%) of the patients were smokers. Three patients changed their alcohol consumption and two patients stopped smoking after their TIA of ischemic stroke.

### *Healthy lifestyle perspectives*

All patients mentioned a good diet as positive and smoking as negative in relation with a healthy lifestyle.

*"For me, that means regular nutrition, but vegetables, fruit and not too much." (07, M80)*

*"Just a normal life, quit smoking, reducing alcohol and a healthy lifestyle." (09, M59)*

Most participants named exercise as part of a healthy lifestyle, and alcohol intake as unhealthy.

*"A lot of exercise, healthy eating. And smoking is not a part of this and not drinking."  
(03, M53)*

*"Smoking is bad, alcohol is bad and eating fat is bad." (16, V48)*

Many aspects on what a healthy lifestyle should include were mentioned. A patient remarked that food should be eaten throughout the day and patients mentioned that the diet should not contain too much fat. Another patient thought that drinking a lot of water is important.

*"Do not eat fat. And move a lot and drink well, drink lots of water. Lot of raw vegetables and .. fish .. chicken and something you know .." (18, V72)*

Patients reported that working in their garden, walking with the dog or walking stairs at work was enough exercise during the day.

*"Movement, yes I have enough. I walk up and down the stairs all day and go to the studio." (009, M59)*

More than half of the patients were satisfied with their own lifestyle. One third of the patients rated their dietary pattern as good, and felt no need to change.

*"No complaints about my lifestyle. Because I feel pretty good now, why would I change things." (01, M71)*

### **General barriers and facilitators**

Five patients named lack of knowledge as a barrier for behavior change, in particular in relation to dietary behavior.

*"And furthermore they just let me find out ... they just let me figure it all out for myself, they do not say what you can do best." (11, M70)*

Social support was experienced as a facilitator of physical activity. Support of spouses was named by three patients.

*"Yes, I do that with my husband ...that's really nice... I feel his support, like: together we can do this. So that's really nice." (18, V72)*

Some patients appear to have a low perceived severity of their ischemic stroke, which leads to the absence of an intention to quit smoking:

*"I simply hate it, but I also hate that nothing comes out of those investigations. And therefore I say, well if there is anything that they see, something in my brains, well if there is a bit of a scar, they can see something, then I'm like: shit. But now I just haven't yet." (10, V48)*

However for one participant severity appeared to be a facilitating factor to quit excessive alcohol intake. According to this patient it was a choice between drinking and dying or quit drinking and stay alive. Severity has not been mentioned in relation to other health-related behavior.

### **Self-efficacy**

Self-efficacy was most common mentioned as a barrier or facilitator of health-related behavior change.

*"Self-confidence I need to have again ... Yes, I want to quit, but I can't. I can't." (004, V66)*

*"I do want to change that, but I just can't keep up with that. Sometimes it works, most of the time it doesn't." (005, V55)*

Mental, physical and environmental barriers were barriers for health-related behavior change. Mental barriers were mainly mentioned in relation to smoking habits.

*"Because I feel so much stress. And then I think, now that I had this, this year sucks. ... if I have to quit now, I don't have anything left, I feel a bit like that." (010, V48)*

Mood and cognitive problems were also experienced as a mental barrier for health-related behavior change in four patients.

*"When I am a bit depressed, yes I smoke a bit more, but well then, then I think something like ten cigarettes a day." (004, V66)*

Physical complaints, such as pain and fatigue were remarked as most experienced barrier for physical activity.

*"I do something and then I am tired and then I sit down again, I am tired very quickly, that is the difference. I am tired very quickly. Since I've had this, yes." (005, V55)*

Also environmental barriers were mentioned. Bad weather (cold or rain) was mentioned as a barrier for physical activity.

*"Oh, I can't stand the cold. Because of the blood pressure and vessels. So I stay at home." (04, V66)*

One patient found it hard to eat healthy because of bad eating habits of her partner.

### **Response efficacy**

Response efficacy was mentioned in relation with all types of health-related behavior change. Patients experienced response efficacy mostly as facilitating factor for behavior change.

*"If I can keep up with that . . . , then my chances of getting another stroke are just as high as any other." (8, M66)*

Response efficacy was especially mentioned in relation with changing eating habits and alcohol use.

*"That's because of the cholesterol, it was too high in my opinion. Because of junk food. So I ate less of that." (12, M68)*

*"Before this time I drank one or two glasses of beer, not much and not in one time, but really one or two glasses. But that's not good for this (points at his belly). It increases your blood pressure and thickens your blood." (8, M66)*



Low response efficacy was remarked as a barrier for changing physical activity behavior in six patients. Four patients did not believe that quitting smoking would help.

*"And do more sports, but sport does not affect that at all, in my eyes! If you hear all those stories from those doctors ... Anybody just can get it." (011, V70)*

*"Yeah, what I had, has nothing to do with smoking (partner: but with vessels and other things) well my vessels are OK, the doctor said. But now, I'm appeasing myself, but okay" (15, M73)*

### **Fear**

Nine patients regarded fear of recurrence a facilitating factor for behavior change in general. One patient mentioned that by seeing other (worse) stroke patients, she developed the motivation to change her health-related behavior.

*"Maybe that was 'the light', because I've also seen people there hey, they didn't look very good .. if you come out like that, with a crooked mouth ... people will really notice. That people who were lying next to me couldn't speak well and then, well let's say I'm lucky. But you'll think about it and then you'll go change something, a different lifestyle." (17, M66)*

When asking which factors played a role in quitting smoking and reducing alcohol use, one patient found fear an important factor.

*"Yes... which factors... fear (partner: fear of recurrence, you start thinking about it... because it went well this time but...)" (9, M59)*

Also, one patient found the ischemic stroke was a wake-up call and knew that it could happen again. Another patient tried to eat healthier because of fear of recurrence. Fear has also been mentioned as a facilitating factor by a participant who stopped smoking in the past because of fear of lung diseases.

*"But that fear is the driving force to maintain healthy things." (008, M66)*

Two other participants weren't aware of the risk of smoking on TIA or ischemic strokes and didn't feel fear of recurrence by keeping smoking.

*"Yes well I had this, but stop smoking: no. Maybe as a second MRI shows something, that I think: oh." (10, V48)*

*"Nonsense. Well nonsense, but twenty years ago the doctor and the cardiologist were smoking next to your hospital bed ... they're all still alive that people .. I mean .. I don't want to say that smoking is healthy, but we should not all exaggerate with each other, but well, it is unhealthy, I completely agree with you, but I already reduced smoking" (15, M73)*

### **Hospital advices**

Most patients received advices on health-related behavior during their stay in the hospital or visit to the outpatient clinic. This consisted according to the patients of the following advice: taking rest, eat healthy, stay in condition and use their medication. Some patients didn't receive any advice because they didn't consider it necessary.

*"Yeah it's all very logical. When you just read something here and there about physical activity, don't smoke, drink less alcohol, so I think, half of that I already do." (7, M80)*

More than half of the patients did not need any support to change their health-related behavior. They mentioned that they had enough knowledge of what was right because of the hospital advice or their own knowledge.

*"No, I already know. I know enough and when I don't, I will find out myself" (6, M66)*

Most patients who quit smoking in the past did this without support. Patients also learned about healthy lifestyle because of relatives who received advices.

*"Well ehh, my father has had quite a bit of raised cholesterol for a while, so you already know something about it and you hear and you read something ... and I actually knew it, but I had also received a brochure. [and did you benefit from that brochure] No actually not, no .. no actually more, it actually contained what I already knew." (16, V64)*

### **Support needs**

Some patients needed more information about what they can do themselves to prevent another TIA or ischemic stroke. In addition, there was also a need for guidelines on what

is allowed and what is not allowed. In particular advices on healthy diet would be helpful according to three patients.

*"That you get a little more guidance. Whether it is from the specialist or from the doctor, is not important, only that you have a little more guidance, this is good and this is not good." (3, M53)*

Two patients would like support, but had no idea which support could be effective in relation to stop smoking and increasing physical activity.

*"I would not know. I cannot imagine anything at all." (4, V66)*

Patients would like to have professional support in changing behavior and healthy life-style preservation mainly in improving physical activity. Three participants were currently receiving support from a physical therapist for physical activity. To maintain physical activity, one participant also received a training schedule from the physiotherapist to continue at home. Support of a sports instructor was also mentioned.

*"Yes and it is, also because it is in [place name], a small gym, there is only one man .. but if I go there at half past 12 or so then you have a personal trainer, then I am alone or there are two or so and then ... he really thinks about it .. what exercise is good for you" (16, V64)*

Another participant also goes to a sports instructor for person-specific training schedules.

*"And then I get a schedule with pictures and I have to do that for six weeks, and after six weeks we evaluate that and then I get something else or you continue to see if the pace is increased, things like that. So a bit under supervision. That goes well in the gym." (12, M68)*

One patient mentioned support of a GP by increasing physical activity. The doctor could give support by monitoring the blood pressure and the cholesterol level, so that the patient remains more motivated to keep it up.

*"Maybe the doctor, ... actually the doctor has to regularly measure blood pressure and cholesterol. So, we also have agreements for that. Maybe the doctor could mean something in that. I think so, I think it will matter to me. But for the time being I will get up every morning and get on my bike." (8, M66)*

Support by a dietician for changing diet has been mentioned by one male participant in order to get some more guidelines for good cholesterol levels. One participant already had a dietician for, among other things, diet plans.

*"She finds schedules for me for food, for sports and for weight ... I wanted to lose 10 kilos, because I had gained 10 kilos after that accident. And half of that is now reached, still five kilos .. and she will accompany me for a few months. And she always sends me these things [applications]." (12, M68)*

Social support has been mentioned in different ways. Some participants currently get emotional support to move more. For example, one patient receives support from his wife when walking and others receive encouragement from their partner to get more exercise.

*"Yes, I will cycle with her. Yes since now. She likes being with me, because she is not yet completely sure what I can, and cannot do, by the way. She does it more for me, by the way, protecting or controlling me may be too big a word. Yes, I am not so afraid of that now, but okay, if it makes her feel safer, that's good." (3, M53)*

Patients also named the importance of support in quitting smoking and in insisting on reducing alcohol consumption.

*"Nothing. Yes, my daughters and son. They also say: not too much!" (9, M59)*

## Discussion

Patients understand what constitutes a healthy lifestyle, but seem unable to adequately appraise their own health-related behavior. More than half of the patients were satisfied with their lifestyle and had no urgency to change. Self-efficacy was the most important determinant for health-related behavior change. It was mentioned both as barrier and facilitator. The majority of the patients did not need support or already received support in changing their lifestyle. Patients indicated knowledge, guidelines and social support as most needed to change health-related behavior and to preserve a healthy lifestyle. Participants know what a healthy lifestyle consists of, but it was unclear to what extent participants were able to assess their own lifestyle as we did not assess their actual health-related behavior in this study. Earlier studies also showed that risk assessment and knowledge about risk factors is not optimal after ischemic stroke.<sup>[16]</sup> In our study patients also indicated knowledge and guidelines as facilitating factors for health-related behavior change. Several previous studies showed that many stroke patients express a lack of understanding and desire for further knowledge about all aspects of stroke disease.<sup>[24]</sup>

Besides knowledge, social support has been indicated as most needed to change behavior. In line with this result social support has been found as important factor for changing physical activity after stroke in many other studies.<sup>[18, 25-30]</sup> Low self-efficacy appeared to be the strongest barrier for behavior change after TIA or ischemic stroke. Self-efficacy has been found to have a direct effect on health-related behavior and is the strongest predictor of health-related behavior change.<sup>[31]</sup> In our previous study,<sup>[32]</sup> we found that self-efficacy was the strongest determinant of intention to stop smoking, increase physical activity and improve healthy diet. Self-efficacy was a powerful predictor of intention to change in other cardiovascular studies.<sup>[33-37]</sup> Therefore self-efficacy can be seen as a barrier and facilitator as patients in our study mentioned. Response efficacy and fear were also named as facilitating factors. In line with our results, earlier studies in cardiovascular and stroke patients showed response efficacy and fear as determinants of health behavior change.<sup>[38, 39]</sup> Fear of a recurrent stroke is often present<sup>[40-44]</sup> and leads to a motivation to make changes to promote patients' health in order to avoid a new stroke.<sup>[40]</sup> In our previous study fear of recurrence and response efficacy were also determinants of intention to change health behavior after TIA or ischemic stroke.<sup>[20]</sup> To the best of our knowledge there are no other studies focussing on fear and response efficacy in relation to actual health-related behavior change in patients with TIA or ischemic stroke.

The results of our study show that patients after TIA or ischemic stroke often feel no urgency to change. Patients may not have enough knowledge to properly assess their lifestyle and severity of stroke recurrence. Stroke patients are known to have a low awareness of risk factors for stroke. However, patients indicated to have sufficient knowledge and most patients indicated that they did not need support. When patients felt the need to change, they indicated knowledge as the most necessary factor for changing health-related behaviors and felt the need to know more about guidelines. Several patients mentioned fear as a facilitator for health-related behavior change. However, this fear will increase if patients have sufficient knowledge to estimate the severity. Besides knowledge, self-efficacy appeared to play an important role. When patients are convinced of the importance of behavioral change and have enough knowledge of the guidelines, self-confidence is needed to proceed to actual change. Response efficacy was also mentioned as a facilitator of health-behavior change. It may be an important determinant as behavior change is hard to accomplish and patients are only willing to change when they believe that making the change is effective in reducing the risk of other events. Lack of knowledge can also play a role in this determinant. If patients are not aware of the effects of health-related behavior change, they will be less likely to change. In our earlier study we found a gap between intention and actual change. Patients had the intention to change and high self-efficacy and fear were present, but there was no actual change. Possibly these patients

did not know how to change their lifestyle, as patients in our present study mentioned knowledge and guidelines as the most needed factor to health-related behavior change and to preserve a healthy lifestyle. However, knowledge is not sufficient to adopt a healthy lifestyle, because other barriers to behavioral change often overrule the advice.<sup>[11,37]</sup> If there is sufficient knowledge but self-efficacy is low, it will be difficult to proceed to actual change. Only two studies focused on knowledge in relation to health-behavior change in patients with ischemic stroke. Both studies found no difference in behavioral change in lifestyle.<sup>[15, 38]</sup> Next to self-efficacy, action planning and action control are crucial to bridge the gap between intentions to change behavior and actual behavior change and behavior maintenance. Action planning means that it is important to make a detailed mental representation of “when”, “where” and “how” an intended behavioral action has to be performed. Action control is a self-regulatory process of *self-monitoring* one’s own behavior, *awareness* of the intended behavior, and the *effort* one makes in performing the intended behavior.<sup>[34]</sup> Therefore interventions focusing not only on increasing self-efficacy and self-management, but also on action planning and action control can possibly bridge the intention behavior gap in these patients.

Strength of this study is that patients were interviewed at home in their own environment. Therefore social desirability does not seem to play a large role in this study. Another strength is the qualitative aspect of this study. As far as we know patients’ perspectives on determinants of health-related behavior change after ischemic stroke have not been studied qualitatively before. Since many discussion points returned and were comparable between patients saturation was reached, and the sample of 18 patients seems to have been taken properly. This study has also some limitations. Patients do not seem to adequately appraise their lifestyle. We cannot be sure how much this judgment differs from the actual lifestyle of the patients as we have not assessed their actual health-related behavior. We should have assessed their actual lifestyle more thorough. When patients think they have a healthy lifestyle a conversation about changing health behavior can be difficult. Therefore it possibly would be better to use questionnaires to assess their lifestyle first. Another limitation is the use of semi-structured interviews. Although the interview was as open as possible, sometimes the interviewer did a suggestion which gave the patient a direction, because some issues had to be addressed. On the other hand, some determinants, like “perceived severity” were still not discussed much. The short time between the ischemic stroke or TIA and the interview has advantages and limitations. On the one hand, patients just experienced their ischemic stroke or TIA and made decisions about their behavior change. On the other hand some patients did not think about their health behavior yet at the time of the interview and were mainly focused on recovering.

## **Conclusion**

In conclusion, this study suggests that patients with recent TIA or ischemic stroke do not have a proactive approach towards health-related behavior change. Patients understand what constitutes a healthy lifestyle, but seem unable to adequately appraise their own health-related behavior.

## **Practice implications**

In this study more than half of the patients felt no urgency to change their lifestyle. Patients indicated that knowledge and guidelines for healthy lifestyle can help in changing health behavior. Possibly these findings are related as patients are not able to assess their lifestyle properly as knowledge of what a healthy lifestyle entails is missing. Increasing knowledge could therefore not immediately increase the motivation for change, but possibly increase the awareness of what a healthy lifestyle consists of and how the patient's current lifestyle relates to this. Increasing awareness could therefore be a first step towards change. In addition, self-efficacy also appears to play a major role in changing the lifestyle in this study. Future studies should therefore focus on investigating opportunities to effectively increase knowledge, awareness and self-efficacy to promote lifestyle change.

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# Chapter

# 1.3



# Self-efficacy for health-related behavior change in patients with TIA or minor ischemic stroke

D. Brouwer-Goossensen

L. van Genugten

H.F. Lingsma

D.W.J. Dippel

P.J. Koudstaal

H.M. den Hertog



## ABSTRACT

**Objective:** To assess levels of self-efficacy for health-related behavior change and its correlates in patients with TIA or ischemic stroke.

**Methods:** In this prospective cohort study, 92 patients with TIA or ischemic stroke completed questionnaires on self-efficacy for health-related behavior change and fear, social support and depressive symptoms. Relations between fear, social support, depressive symptoms, cognitive impairment, vascular risk factors and history, and demographic characteristics and low self-efficacy were studied with univariable and multivariable logistic regression.

**Results:** Median total self-efficacy score at baseline was 4 (IQR 4-5). Older age (OR 1.05, 95% CI 1.01-1.09), depressive symptoms (OR 1.09, 95% CI 1.03-1.16), presence of vascular history (OR 2.42, 95% CI 0.97-6.03), higher BMI (OR 1.15, 95% CI 1.01-1.30), fear (OR 1.06, 95% CI 1.01-1.12) and low physical activity (OR 1.49, 95% CI 1.01-2.21) were significantly associated with low self-efficacy.

**Conclusion:** Patients with recent TIA or ischemic stroke report high self-efficacy scores for health-related behavior change. Age, vascular history, more depressive symptoms, higher BMI, less physical activity and fear were correlates of low self-efficacy levels.

**Practice implications:** These correlates should be taken into account in the development of interventions to support patients in health-related behavior change after TIA or ischemic stroke.

*Published in Psychology and Health, Dec 2018*

## Background

The modification of health behavior is an important part of cardiovascular disease risk management. Secondary prevention programs focusing on lifestyle modification, such as cardiac rehabilitation have positive effects on health outcomes. However, for patients with stroke or TIA (defined by Easton et al., 2009 as brief episodes of neurological dysfunction resulting from focal cerebral ischemia not associated with permanent cerebral infarction), insufficient data are available on the effect of lifestyle modification and current guidelines were drawn on data extrapolated from epidemiological studies or cardiac rehabilitation.<sup>[1-7]</sup> Moreover, studies have shown that the majority of people with cardiovascular disease fail to sustain lifestyle modification in the long-term.

The social cognitive theory describes how cognitive, behavioral, personal and environmental factors determine behavior and motivation.<sup>[8,9]</sup> One of the factors that play a central role in this process is perceived self-efficacy. Self-efficacy (a person's confidence to carry out behavior necessary to reach a desired goal) is an important precondition for successful self-management.<sup>[10,11]</sup> In our previous study<sup>[12]</sup> we found that self-efficacy was the strongest determinant of intention to stop smoking, increase physical activity and improve healthy diet. Self-efficacy was also a powerful predictor of intention to change in other cardiovascular studies.<sup>[10,13-16]</sup> It has been found to have a direct effect on health-related behavior and is the strongest predictor of health-related behavior change.<sup>[15,17]</sup> Hence, increasing self-efficacy could be a way to support health-related behavior change in patients with TIA or ischemic stroke. Modulation of self-efficacy has proven to be effective in changing health-related behavior in patients with overweight and in healthy individuals of different ages<sup>[11-18]</sup> and is for example possible by means of self-management interventions. There is growing evidence that these self-management approaches are effective in increasing self-efficacy.<sup>[18]</sup> The literature on 'self-management' after stroke is limited. Nevertheless a systematic meta-review based on 13 systematic reviews which studies core elements of self-management support including problem solving, decision making, and goal setting found high quality evidence that therapy rehabilitation incorporating these elements delivered soon after a stroke improves ADL and extended ADL and reduces the risk of dependence and mortality. As far as we know there is no clear evidence how to improve self-management for behavior change in stroke patients. At present also little is known about correlates of self-efficacy for health-related behavior change in patients with stroke or TIA and it may be different from other vascular conditions, as stroke patients are generally older and often have cognitive and/or functional impairment. Studies on self-efficacy in patients with TIA or ischemic stroke have shown that patients with high self-efficacy report significantly fewer depressive symptoms, were more likely to meet exercise recommendations, were younger, and not overweight.<sup>[19-</sup>

<sup>22]</sup> However, these studies did not focus on health-related behavior change. In patients with cardiovascular diseases, diabetes and smoking were related to low levels of self-efficacy. <sup>[16]</sup> It is unknown yet if diabetes and smoking are associated with self-efficacy in patients with TIA or ischemic stroke as well.

Self-efficacy can be developed by mastery experiences (successes build a robust belief in one's personal efficacy), vicarious models (rolemodels), social persuasion (social support) and psychological and emotional arousal.<sup>[11]</sup> Social support is therefore an important requirement for health-related behavior change by adequate self-management.<sup>[11,23]</sup> Social support is known to influence physical activity after stroke, but it is unclear whether it has a role in improving self-efficacy.<sup>[24-26]</sup> On the other hand, fear and depression can also affect self-efficacy and are often present after stroke.<sup>[27,28]</sup> An earlier study showed that fear was independently associated with intention to change health-related behavior<sup>[13]</sup> and depression is known to influence health behavior change in myocardial infarction patients.

At present, it is unclear how to support patients in changing health-related behavior after TIA or ischemic stroke. Insight in the correlates of self-efficacy can be helpful by developing interventions to increase self-efficacy and thereby support patients with TIA or minor ischemic stroke with health-related behavior change and to select patient groups on which the interventions should be focused. In this study, we aimed to describe levels of self-efficacy of health-related behavior change and identify correlates of self-efficacy in patients with ischemic stroke or TIA.

## Methods

All patients included in the present study participated in the DECIDE study. Detailed methods of the DECIDE study have been described earlier.<sup>[12]</sup> In short, DECIDE was a prospective study on determinants of intention to change health-related behavior and actual change in patients with TIA or ischemic stroke. Patients of 18 years or older with a clinical diagnosis of TIA, including amaurosis fugax, or minor ischemic stroke with a modified Rankin Scale score (mRS) 2 or less were included during admission on the stroke unit or outpatient clinic.

## Baseline data

We recorded data on clinical features of TIA or ischemic stroke, quantification of stroke severity according to the National Institutes of Health stroke scale <sup>[29]</sup> (NIHSS, a 15-item scale with scores that range from 0 to 42 and higher values indicating greater severity), demographic data, vascular risk factors and history, weight, length, BMI and use of medication. Patient were assessed at baseline (directly after inclusion) and three months



later in the DECIDE study. However, as self-efficacy did not change in this 3-months follow up, we only used baseline data in this study. The assessment included self-reported questionnaires on self-efficacy, fear, social support, depressive symptoms, health-related behavior and social support. Furthermore, all patients underwent a cognitive assessment. The following questionnaires were completed:

- Self-efficacy was measured with the self-efficacy scale, a 7-item scale with scores that range from 1 to 5.<sup>[30]</sup> Higher values indicate more confidence to carry out the behavior necessary to reach the desired goal. Cronbach's  $\alpha$  of the self-efficacy questionnaire was 0.75. This scale has been used successfully before in in vascular patients.<sup>[10, 16, 31, 32]</sup>
- Fear was assessed with 8 questions. Patients were asked on a scale of 1 to 5 how nervous they are when thinking of getting another stroke, how upset they get, depressed or jittery, if their heart beats faster, and if they feel uneasy or anxious.<sup>[33]</sup>
- Social support was evaluated with the aspects of Active engagement, Protective buffering, and Overprotection (ABO) social support questionnaire for Dutch coronary heart disease patients.<sup>[34]</sup> This questionnaire includes 5 statements about active involvement, 8 statements concerning protective buffering, and 6 about overprotection, of which respondents can respond on a 5-point scale, ranging from (0) 'very often' to (4) 'never'.
- Depressive symptoms were assessed with the CES-D (centre for Epidemiologic Studies Depression Scale) for both depression and anxiety.<sup>[35, 36]</sup> Higher scores indicate more depressive symptoms.
- Physical activity was assessed with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire. Patients were asked to report activities performed for at least 10 minutes during the last 7 days, and time spent in physical activity performed across leisure time, work, domestic activities, and transport at each of 3 intensities: walking, moderate, and vigorous.<sup>[37]</sup> We used reported minutes of moderate and vigorous physical activity to calculate a total physical activity score of minutes a day. As included patients had a mRS score of 2 or less they were able to walk without assistance and look after their own affairs without assistance.
- Dietary behavior was assessed with the short Food Frequency Questionnaire (FFQ). This 14-item scale assesses the intake of saturated fatty acids, unsaturated fatty acids,

and fruits and vegetables over the week before the visit. An overall cardiovascular dietary score was calculated, ranging from -17 to +19, the higher the score, the more favorable the dietary pattern.<sup>[38]</sup>

- Smoking status was assessed with questions on current smoking status, how many years they have smoked, and how much cigarettes a patient smokes a day. Smoking was defined as current smoking.
- Cognitive impairment was assessed with Montreal Cognitive assessment (MoCA), a rapid screening instrument for cognitive impairment, in particular for stroke patients.<sup>[39]</sup>

### Statistical analysis

Self-efficacy was dichotomized into high self-efficacy and low self-efficacy based on the median self-efficacy score. Differences in demographic data, event characteristics, vascular history and risk factors, health-related behavior, cognition, depressive symptoms, fear, and social support, between low and high self-efficacy were studied with t-tests. Non-normal distributed data were analyzed with Mann-Whitney U tests. We studied the relation between correlates of behavior change and low self-efficacy with univariable logistic regression analysis. Physical activity was unequally distributed and was log transformed, before the univariable linear regression analysis. Correlates with a p-value of <0.06 were further analyzed with multivariable logistic regression. The relation between correlates and continuous self-efficacy score were also analyzed in univariable and multivariable linear regression. Statistical analysis were performed with STATA 12.1 statistical package (Statacorp, College Station, Texas).

### Results

Ninety-two patients were included between February and October 2012. Mean age was 64 years (SD 12), 55 (60%) of the patients were male and 49 (53%) had a TIA (Table 1). Patients had a moderately healthy lifestyle; median physical exercise was 137 minutes a day (interquartile range 62-219), mean BMI was 27 (SD 3.6) and median overall diet score 0 (interquartile range -2-2). Only 5 (6%) patients used more alcohol than advised and 32 (35%) of the patients were smokers.

Median total self-efficacy score at baseline was 4.3 (IQR 3.9-4.7, Table 2) and self-efficacy didn't change in three months follow-up (data not shown). Thirty patients (33%) had low self-efficacy scores for health-related behavior change.

**Table 1:** Baseline characteristics and dichotomized self-efficacy at baseline and its determinants (N=92)

	Overall	High	Low	p
Age (years), mean (SD)	64 (12)	61 (52-70)	69 (61-75)	0.02
Sex (male), n (%)	55 (60)	38 (61)	17 (57)	0.68
<i>Event characteristics:</i>				
Event type (TIA), n (%)	49 (53)	34 (55)	15 (50)	0.67
Right hemisphere	38 (44)	13 (57)	23 (40)	0.19
NIHSS score <sup>1</sup> , median (IQ)	3 (1-5)	2 (1-5)	3 (1-5)	0.41
mRS, median (IQ)	1 (0-2)	1 (0-2)	1 (0-2)	0.24
<i>Vascular history, n (%)</i>				
Vascular history <sup>2</sup>	48 (52)	28 (45)	20 (67)	0.05
TIA	16 (17)	13(19)	3 (13)	0.47
Ischemic stroke	14 (15)	8 (12)	6 (25)	0.12
Ischemic heart disease	33 (36)	21 (31)	12 (50)	0.10
Atrial fibrillation	11 (12)	7 (10)	4 (17)	0.41
Peripheral arterial disease	6 (7)	5 (7)	1 (4)	0.59
<i>Cognition and depression:</i>				
MoCA <sup>3</sup> , median (IQ) scores from 0-30	24 (21-26)	25 (22-26)	23 (20-25)	0.09
CES-D <sup>4</sup> , median (IQ) scores from 0-30	7 (5-13)	7 (4-10)	13 (6-19)	0.00
<i>Lifestyle:</i>				
Smoking, n(%)	32 (35)	21 (34)	10 (33)	0.96
Alcohol abuse, n (%)	5 (5.6)	4 (7)	1 (3)	0.54
Physical exercise <sup>5</sup> (min/day), median (IQ)	137 (62-219)	166 (73-283)	99 (42-180)	0.05
Dietscore <sup>6</sup> , median (IQ) range -17 to +19	0 (-2-2)	0 (-2-2)	1 (-2-4)	0.42
BMI (kg/m <sup>2</sup> ), mean (SD)	26,6 (3.6)	26.0 (3.1)	28 (4.4)	0.03

**Table 1:** Baseline characteristics and dichotomized self-efficacy at baseline and its determinants (N=92)

	Overall	High	Low	p
<i>Vascular risk factors:</i>				
Hypertension <sup>7</sup> , n (%)	61 (66)	39 (63)	22 (73)	0.33
Systolic blood pressure (mmHg), mean (SD)	136 (23)	135 (125-145)	135 (121-148)	0.64
Diastolic blood pressure (mmHg), mean (SD)	79 (13)	80 (72-89)	79.5 (70-86)	0.53
Hypercholesterolemia <sup>8</sup> , n (%)	75 (82)	52 (84)	23 (77)	0.41
Total cholesterol level (mmol/l), mean (SD) <sup>9</sup>		5.2 (3.9-6.1)	4.9 (4.3-5.3)	0.66
Blood glucose level (mmol/l), mean (SD) <sup>9</sup>	6.0 (1.5)	5.6 (5.1-6.2)	5.7 (5.2-6.6)	0.42
Diabetes Mellitus <sup>10</sup> , n (%)	28 (30)	17 (27)	11 (37)	0.37
Fear <sup>11</sup> , median (IQ) scores from 0-32	16 (8-21)	13 (7-18.5)	17 (12-23)	0.02
<i>Social support</i> <sup>11</sup> :				
Active involvement, median (IQ)	15 (12-17)	15 (12-17)	17 (10-16)	0.50
Protective buffering, median (IQ)	11 (7-14)	11 (7-14.5)	12 (8-14)	0.72
Overprotection, median (IQ)	7 (4-11)	6 (4-11)	9 (4-12)	0.18

<sup>1</sup> Quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS), a 15-item scale with scores that range from 0 to 42 and higher values indicating greater severity.

<sup>2</sup> Classification of subtype of acute ischemic stroke developed for the Trial of Org 10172 in Acute Stroke Treatment (TOAST).

<sup>3</sup> Assessed with the Minimal Mental State Examination and Montreal Cognitive assessment (MoCA).

<sup>4</sup> Scored with the Centre for Epidemiologic Studies Depression Scale (CES-D)

<sup>5</sup> Measured with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire.

<sup>6</sup> Evaluated with the short Food Frequency Questionnaire (FFQ). The higher the score, the more favorable the dietary pattern.

<sup>7</sup> Hypertension has been defined as systolic blood pressure higher than 140 mmHg and diastolic higher than 90 mmHg or antihypertensive medication use at baseline.

<sup>8</sup> Hypercholesterolemia has been defined as a total cholesterol of 6.0 mmol/l and/or statine use at baseline.

<sup>9</sup> Measured between day 2-5 after admission, or at visiting date of outpatient clinic

<sup>10</sup> Diabetes mellitus has been defined as fasting glucose level higher than 6.9 mmol/l, and/or glucose level higher than 11 mmol/l after oral glucose intolerancetest, and/or diabetes mellitus in history and/or antidiabetic medication use at baseline.

<sup>11</sup> Fear measured with 8 questions, asking on a scale of 1-5 how nervous patients are when thinking of getting another stroke, how upset they get, depressed or jittery, if their heart beats faster, they feel uneasy or anxious.

<sup>112</sup> Measured with the Active engagement, Protective buffering, and Overprotection (ABO) social support questionnaire for Dutch coronary heart disease patients<sup>[29]</sup>

**Table 2:** Self-efficacy for behavior change

	Baseline
Total, median (IQ)	4.3 (3.9-4.7)
Medication, median (IQ)	5 (5-5)
Smoking, median (IQ)	4 (3-5)
Diet at home, median (IQ)	5 (4-5)
Diet when not at home, median (IQ)	4 (4-5)
Physical activity, median (IQ)	5 (4-5)
Weight maintenance, median (IQ)	4 (4-5)
Weight reducing, median (IQ)	4 (3-5)

Older age (OR 1.05, 95% CI 1.01-1.09), depressive symptoms (OR 1.09, 95% CI 1.03-1.16), vascular history (OR 2.42, 95% CI 0.97-6.03), higher BMI (OR 1.15, 95% CI 1.01-1.30), higher fear (OR 1.06, 95% CI 1.01-1.12) and low physical activity (OR 1.49, 95% CI 1.01-2.21) were significantly associated with low self-efficacy for improving health-related behavior change, with BMI and depressive symptoms as the strongest correlates (Table 3 and 4).

**Table 3:** Relations between dichotomized self-efficacy and correlates of behavior change univariable and multivariable logistic regression analysis

	OR (95% CI)	p	aOR (95% CI)	p
Age	0.95 (0.92-0.99)	0.02	0.95 (0.90-1.00)	0.07
Vascular history	0.41 (0.17-1.02)	0.06	0.61 (0.19-2.05)	0.43
Ces-d	0.92 (0.86-0.97)	0.01	0.91 (0.84-0.99)	0.03
BMI	0.87 (0.77-0.99)	0.03	0.79 (0.65-0.96)	0.02
Fear	0.94 (0.89-0.99)	0.02	0.96 (0.89-1.03)	0.26
Physical activity	1.49 (1.01-2.21)	0.05	1.58 (0.95-2.64)	0.08

**Table 4:** Relations between correlates and self-efficacy, univariable and multivariable regression analysis

	Beta (CI)	p	aBeta (95% CI)	p
Age	-0.00 (-0.02-0.00)	0.14	-0.00 (-0.02-0.00)	0.07
Vascular history	-0.21 (-0.48-0.07)	0.14	0.05 (-0.21-0.32)	0.69
Ces-d	-0.04 (-0.05- -0.02)	0.00	-0.02 (-0.04-0.01)	0.01
BMI	-0.05 (-0.09- -0.01)	0.01	-0.05 (-0.10- -0.02)	0.01
Fear	-0.03 (-0.04-0.01)	0.00	-0.02 (-0.03-0.00)	0.06
Physical activity	0.03 (-0.08-0.14)	0.56	0.04 (-0.07-0.15)	0.50

## Discussion and conclusion

In this study, we found that patients with recent TIA or ischemic stroke report high self-efficacy scores for health-related behavior change. Older patients, and those with vascular history, more depressive symptoms scores, higher BMI, less physical activity and increased fear had lower levels of self-efficacy for health-related behavior change. Of these prognostic factors, depressive symptoms and BMI were the strongest (Table 4).

This is one of the first studies that assessed correlates of self-efficacy for health-related behavior change in patients with TIA and minor ischemic stroke. Self-efficacy for behavior change appeared to be high in our patients as earlier studies using the same self-efficacy scale<sup>[16, 31, 32]</sup> found comparable total self-efficacy scores, but disaggregated self-efficacy scores were lower. In line with our results, two other studies showed that patients with high self-efficacy had significantly less depressive symptoms<sup>[19-21]</sup>, were more likely to meet exercise recommendations<sup>[21, 22, 32]</sup> were younger, and not overweight.<sup>[16, 22]</sup> In studies with patients with vascular disease (coronary heart disease, cerebrovascular disease or peripheral artery disease) having diabetes and smoking were significantly associated with lower levels of self-efficacy in contrast to our results.<sup>[16, 32]</sup> We found only one study in which vascular history as determinant of self-efficacy for health-related behavior change was studied in patients with vascular diseases. In this cross-sectional study with 236 patients, no association between vascular history and self-efficacy was found.<sup>[16]</sup> As far as we know, fear has not been studied in relation to self-efficacy for health-related behavior change in patients with TIA or ischemic stroke or other vascular diseases. Earlier studies in general populations showed a significant interaction between threat (fear) and self-efficacy, such that threat only had an motivating effect when high efficacy is present.<sup>[40]</sup> The association between low self-efficacy scores for behavior change and depressive symptoms has also been earlier described in general populations.<sup>[41, 42]</sup> Social support is considered to be an important requirement of health-related behavior change by adequate self-management,<sup>[11, 23]</sup> but in our study we found no relation between social support and self-efficacy.

A strength of our study is that we collected detailed information on potential correlates of self-efficacy. This included both patient characteristics and correlates of health-related behavior change. Our study also has some limitations. First, we studied patients for a relatively short period of time after their TIA or minor ischemic stroke. In this period, patients possibly did not adequately appraise their situation. On one hand this effect may not be very strong, because self-efficacy did not change over a period of three months. On the other hand patients often rehabilitate in the first months after discharge. The positive feedback and support in this period can provide a boosting effect on self-efficacy. Second, self-efficacy for health-related behavior change appeared to be high in patients with TIA

or minor ischemic stroke. The self-efficacy scale used in our study has only been applied in three earlier studies in patients with symptomatic vascular diseases (cerebrovascular disease, abdominal aortic aneurysm, or peripheral arterial disease). In these studies, total self-efficacy was comparable to our findings, but disaggregated self-efficacy scores were lower.<sup>[16, 31, 32]</sup>

Furthermore, social desirability bias during questionnaire completion may also have played a role as self-efficacy is high in these patients where our earlier study showed that most patients do not actually change their behavior, due to the intention-behavior gap.<sup>[12, 43]</sup> Sol et al. described how subsequent underestimation of the difficulty of self-management of vascular risk can be another explanation for high self-efficacy scores.<sup>[31]</sup> The questions seem simple, causing high scores while the tasks are very difficult. We analyzed several correlates in this study which can lead to type 1 errors. Also it cannot be completely excluded that our results were affected by possible confounders. Although for instance the low mRs and NIHSS suggests that these patients are mildly or not impaired, factors such as fatigue, visual loss or inactivity can affect the relation between physical activity and self-efficacy as well. There was also a small (but not significant difference) in cognition between patients with high-self efficacy and low self-efficacy. However in linear regression analysis (adjusted for age, data not shown) we found no significant relation between self-efficacy and cognition.

The results of our study suggest that vulnerable patients have lower self-efficacy scores. Older patients often experience more physical discomfort that may result in feeling less confident. Also vascular history or depressive symptoms can affect the patients' perception of their physical and mental capability, resulting in low self-efficacy. Patients with higher fear had lower self-efficacy levels. In contrast to our study, a meta-analysis of fear studied in different populations and different behaviors has shown a significant interaction between threat (fear) and efficacy, in these studies threat only had a motivating effect when high efficacy is present.<sup>[40]</sup> Possibly, fear results in counterproductive behavior in our patients, and leads to avoidance or denial based forms of coping, explaining the association with low self-efficacy. We expected social support to play a role in building self-efficacy, as it plays a role in self-management. However we found no relation between social support and self-efficacy. Possibly social support influences self-management in an different kind than by improving self-efficacy. For example the effect of old age, vascular history and fear on self-efficacy can be so intense that the social support patients experience cannot compensate the effects of these correlates.

At present, the mechanism of building self-efficacy is not completely clear. On the one hand, factors as vascular history, age, depressive symptoms and fear can influence self-efficacy. On the other hand, self-efficacy may influence these factors as well. For example, lack of confidence and low self-efficacy can possibly lead to less control of health-related related behavior resulting in overweight, less physical activity and continuing smoking. Vice versa, being overweight, less physical active or not being able to quit smoking can also affect the sense of control over one's life with consequently low self-efficacy.

Self-efficacy is an important precondition for behavior change. Therefore, increasing self-efficacy could be a way to support health behavior change in patients with TIA or ischemic stroke. As far as we know, a few studies focused on improving self-efficacy or self-management in patients with TIA or ischemic stroke,<sup>[44-47]</sup> but we identified only one study which focused on self-efficacy for health-related behavior change.<sup>[31]</sup> In this study self-efficacy for healthy food and physical exercise improved by the nursing intervention. As self-efficacy can be developed by mastery experiences (successes build a robust belief in one's personal efficacy), vicarious models (rolemodels), social persuasion (social support) and psychological and emotional arousal,<sup>[11]</sup> these self-management programs should be built on these factors. Motivational interviewing can also be used to help patients exercise more, lose weight, reduce problematic substance use and stimulate self-efficacy in their ability to make health-related behavior changes.<sup>[48]</sup>

Our study provides insight in self-efficacy and factors associated with self-efficacy in patients with a recent TIA or minor ischemic stroke. Future studies should focus on interventions that can influence self-efficacy and should focus on the effects of supporting these patients in health-related behavior change by increasing self-efficacy.

In the development of interventions to support patients in health behavior change after TIA or ischemic stroke the correlates of self-efficacy can be taken into account. Patients of older age, vascular history, more depressive symptoms scores, low physical activity, higher BMI and increased fear deserve additional attention in these programs, for example by extra visits or more intense support. Self-efficacy can be easily measured and could provide an early and direct indication of patients capability to change and the intensity of support needed. Therefore, a tailored self-management program using motivational interviewing could be a very promising method to support patients in health-related behavior change after TIA or ischemic stroke.



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# Chapter

# 1.4



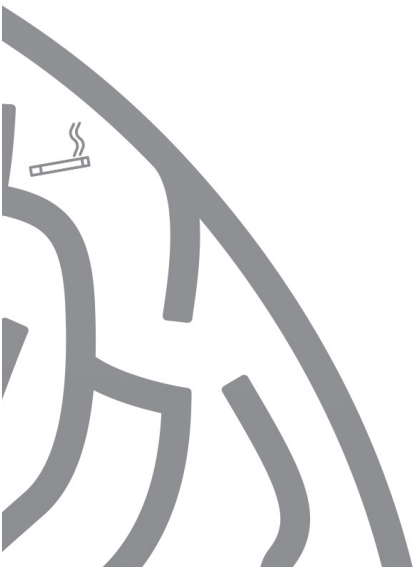
# Determinants of intention to change health-related behavior over time after TIA or ischemic stroke: a prospective cohort study

D. Brouwer-Goossensen

H.F Lingsma

P.J Koudstaal

H.M den Hertog



## ABSTRACT

**Objective:** The optimal timing of an intervention to support health-related behavior after TIA or ischemic stroke is unknown. As the determinants of intention to change health-related behavior probably vary over time, there may be a window of opportunity to start a health-related behavior supporting intervention. We aimed to assess determinants of patients' health-related intention to change over time.

**Methods:** We prospectively studied 100 patients with TIA or minor ischemic stroke. Patients completed questionnaires on fear, response-efficacy (believe that lifestyle change reduces risk of recurrent stroke), and self-efficacy (patients' confidence to carry out lifestyle behavior) for behavior change, at baseline, six weeks and at 3 months after their TIA or ischemic stroke. We studied differences between these determinants at each visit by means of Wilcoxon signed rank tests.

**Results:** Median self-efficacy score at baseline was 4.3 (IQR 3.9-4.7), median fear 16 (IQR 7-21), and response efficacy 10 (9-12). Fear was significantly higher at baseline than at 3 months (mean difference 2.0; 95% CI 0.78-3.9) and started to decrease after six weeks. No change in self-efficacy or response efficacy was found.

**Conclusion:** Since fear significantly decreased over time after TIA or ischemic stroke and self-efficacy and response efficacy scores remained high, the optimal moment to start an intervention to support patients in health-related behavior change after TIA or ischemic stroke seems directly after the stroke or TIA.

*Submitted*

## Introduction

Modification of health behavior after TIA or ischemic stroke including smoking cessation, healthy diet and increased physical activity is considered important and strongly recommended in many guidelines.<sup>[1-3]</sup> However, at present little is known about effective interventions to support patients in this health-related behavior change.<sup>[4, 5]</sup> Not only is the available data inconsistent and of varying quality, but the heterogeneity in applied interventions with regards to content, intensity and behavior focussed on makes comparing difficult. Interventions included personal education, exercise or lifestyle classes, motivational counselling (not specified), telephone support, home visits and interviews<sup>[6]</sup>, but follow-up rates are low and patients experience lack of knowledge and social support, pain and fatigue and other barriers.<sup>[7-11]</sup> Insight in determinants of lifestyle behavior change and optimal timing of the intervention is essential to develop a successful intervention to support health-related behavior change.<sup>[12-15]</sup>

The Protection Motivation Theory to examine determinants of lifestyle behavior change after TIA or ischemic stroke has shown to be an useful model for predicting health-protective intentions and behavior changes in other conditions, such as diabetes, coronary heart disease, and breast cancer.<sup>[16]</sup> We earlier found that response efficacy (the believe that lifestyle change can reduce the risk of recurrent stroke), self-efficacy (patients confidence to carry out behavior necessary to reach a desired goal) and fear were determinants of intention to change health-related behavior after TIA or ischemic stroke. Self-efficacy was the strongest determinant of intention to stop smoking, increase physical activity and improve healthy diet.<sup>[17]</sup> Both response efficacy and self-efficacy were associated with intention to change health behavior in other cardiovascular studies<sup>[18-20]</sup>. At present, there are no studies focusing on change of these determinants over time after TIA or ischemic stroke. As these determinants probably vary over time, there may be a window of opportunity to start a health-related behavior supporting intervention.<sup>[21]</sup>

In order to get insight in the timing to start an intervention supporting health-related behavior change after TIA or ischemic stroke, we aimed to assess the determinants of intention to change over time (fear, response efficacy and self-efficacy) in patients with recent TIA or ischemic stroke.

## Methods

All patients included in the present study participated in the DECIDE study (Determinants of intention to change health-related behavior and actual change in patient with TIA or minor ischemic stroke). Detailed methods of the DECIDE study have been described earlier.<sup>[17]</sup> In short, DECIDE was a prospective study on determinants of intention to change

health-related behavior and actual change in patients with TIA or ischemic stroke. Patients of 18 years or older with a clinical diagnosis of TIA, including amaurosis fugax, or minor ischemic stroke with a modified Rankin Scale (mRS) score of 2 or less were included during admission on the stroke unit or outpatient clinic. Patients were excluded if they were discharged to a nursing home, were not Dutch-speaking or had severe aphasia. Patients were recruited in the first week after admission to the stroke unit or TIA outpatient clinic. All patients received routine general lifestyle advice including regular physical exercise, healthy diet, and advice against smoking as part of standard care at baseline. The study was approved by national and local institutional ethical review boards and written informed consent was obtained from all patients. The investigation conforms with the principles outlined in the Declaration of Helsinki.

As earlier described in the DECIDE study patients were assessed at baseline (directly after inclusion), at six weeks and three months after inclusion.<sup>[17]</sup> The assessment included self-reported questionnaires on self-efficacy, fear, response-efficacy, and health-related behavior. Patients completed the following questionnaires:

- Self-efficacy was measured with the self-efficacy scale, a 9-item scale with scores that range from 1 to 5.<sup>[22]</sup> Higher values indicate more confidence to carry out the behavior necessary to reach the desired goal. Cronbach's  $\alpha$  of the self-efficacy questionnaire was 0.75. This scale has been used successfully before in vascular patients.<sup>[19, 23-25]</sup>
- Fear was assessed with 8 questions. Patients were asked on a scale of 1 to 5 how nervous they are when thinking of getting another stroke, how upset they get, depressed or jittery, if their heart beats faster, and if they feel uneasy or anxious.<sup>[26]</sup>
- Response-efficacy, assessed with the following statement: 'For me, regular physical activity will reduce my chances of getting another stroke' (1 = strongly disagree; 5 = strongly agree). Similar questions were asked for dietary change and smoking cessation.<sup>[26, 27]</sup>



## Statistical analysis

Statistical analysis was performed with STATA 12.1 statistical package (Statacorp, College Station, Texas). Fear, self-efficacy and response efficacy at baseline, after six weeks and three months were described and differences were tested with Wilcoxon signed rank tests. We studied the relation between determinants of intention to change health-related behavior at baseline and after three months with univariable and multivariable linear regression. Adjustments were made for age, sex, baseline scores and other determinants. For instance in analyzing self-efficacy adjustments were made for age, sex, baseline self-efficacy scores and response-efficacy and fear.

## Results

As described earlier we included 100 patients in the DECIDE study between February and October 2012. Follow up was completed in 87 patients: 5 patients refused follow-up, 1 patient was lost to follow-up, 1 patient was excluded because of severe other comorbidity, 1 because of intracerebral hematoma during follow-up, 2 patients because of misdiagnosis, and 3 patients were discharged to another hospital. No significant differences in baseline characteristics were found between included patients and excluded patients (data not shown). Mean age was 64 years (SD 12), 60% of the patients were male and 53% had a TIA (Table 1). Median self-efficacy score at baseline was 4.3 (IQR 3.9-4.7), median fear 16 (IQR 7-21), and response efficacy 10 (9-12). Fear was significantly higher at baseline than at 3 months (mean difference 2.0; 95% CI 0.78-3.9). This significance remained after adjustment for age, sex, baseline self-efficacy and response efficacy (0.37; 95% CI 0.11-0.64, Table 3). Fear started to decrease after six weeks (median fear at 6 weeks 16, at three months 11;  $p$  0.02). No change in self-efficacy or response efficacy was found. <sup>[17]</sup>

**Table 1:** Baseline characteristics ( N=100)

Sex (male), n (%)	60 (60)
Age (years), mean (SD)	64 (12)
<i>Event characteristics:</i>	
Event type (TIA), n (%)	53 (53)
Stroke etiology (TOAST) <sup>1</sup> , n (%)	
Large vessel disease	13 (13)
Cardiac embolism	15 (15)
Small vessel disease	19 (19)
Other	0
Undetermined	53 (53)
NIHSS score <sup>2</sup> , median (IQ)	3 (1-5)
<i>Vascular history, n (%)</i>	
TIA	18 (18)
Ischemic stroke	15 (15)
Ischemic heart disease	36 (36)
Atrial fibrillation	11 (11)
Peripheral arterial disease	8 (8)
No vascular history	49 (49)
<i>Cognition and depression:</i>	
Score on MoCA <sup>3</sup> , median (IQ) scores from 0-30	24 (21-26)
Score on CES-D <sup>4</sup> , median (IQ) scores from 0-30	7 (5-13)
<i>Vascular risk factors:</i>	
Hypertension, n (%)	65 (65)
Systolic blood pressure (mmHg), mean (SD)	135 (22)
Diastolic blood pressure (mmHg), mean (SD)	78 (13)
Hypercholesterolemia, n (%)	79 (79)
LDL level (mmol/l), mean (SD)	3.17 (1.0)
Blood glucose level (mmol/l), mean (SD)	5.9 (1.4)
Diabetes Mellitus, n (%)	30 (30)

**Table 1:** Baseline characteristics ( N=100)

<i>Health related behavior</i>	
Smoking, n(%)	36 (36)
Alcohol abuse, n (%)	5 (5.2)
Physical exercise <sup>5</sup> (min/day), median (IQ)	129.6 (60-218.6)
Physical exercise > 30 min a day n (%)	75 (87)
Overall dietscore <sup>6</sup> , median (IQ) scores from -17 to +19	1.0 (-2-2.5)
BMI (kg/m <sup>2</sup> ), mean (SD)	26,5 (3.6)
Overweight (BMI>25), n(%)	64 (64)

<sup>1</sup> Classification of subtype of acute ischemic stroke developed for the Trial of Org 10172 in Acute Stroke Treatment (TOAST).

<sup>2</sup> Quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS), a 15-item scale with scores that range from 0 to 42 and higher values indicating greater severity.

<sup>3</sup> Assessed with the Minimal Mental State Examination and Montreal Cognitive assessment (MoCA).

<sup>4</sup> Scored with the Centre for Epidemiologic Studies Depression Scale (CES-D)

<sup>5</sup> Measured with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire.

<sup>6</sup> Evaluated with the short Food Frequency Questionnaire (FFQ). The higher the score, the more favorable the dietary pattern.

**Table 2:** Determinants of health related behavior change after six weeks and three months

	Baseline	6 weeks	p	3 months	p
Self-efficacy total, median (IQ)	4.3 (3.9-4.7)	4.4 (4-4.7)	0.13	4.5 (4-4.8)	0.28
Self-efficacy smokers total, median (IQ)	4.3 (3.9-4.7)	4.2 (3.6-4.3)	0.83	4.4 (3.7-4.9)	0.97
Self-efficacy non-smokers, median (IQ)	4.3 (3.8-4.8)	4.5 (4.3-4.8)	0.24	4.5 (4.2-4.7)	0.46
Response efficacy smokers , median (IQ)	10 (9-12)	12 (12-12)	0.09	10 (8-11)	0.73
Response efficacy non-smokers (IQ)	8 (6-8)	8 (6-8)	1.00	8 (6-8)	0.81
Fear, median (IQ)	16 (7-21)	16 (7-23)	0.83	11 (7-18)	0.02

**Table 3:** Univariable and multivariable relations between determinants of health related behavior change at baseline and after three months

	Beta	p	aBeta	p
Self-efficacy total, median (IQ)	0.55 (0.32-0.78)	0.00	0.64 (0.40-0.88) <sup>1</sup>	0.00
Self-efficacy smokers total, median	0.53 (0.21-0.85)	0.53	0.76 (0.47-1.06) <sup>1</sup>	0.00
Self-efficacy non-smokers, median	0.57 (0.25-0.90)	0.00	0.63 (0.28-0.99) <sup>1</sup>	0.00
Response efficacy smokers	0.08 (-0.23-0.39)	0.61	0.06 (-0.26-0.39) <sup>2</sup>	0.69
Response efficacy non-smokers	0.35 (0.00-0.69)	0.05	0.34 (-0.01-0.71) <sup>2</sup>	0.06
Fear, median (IQ) scores	0.42 (0.25-0.60)	0.00	0.37 (0.11-0.64) <sup>3</sup>	0.01

<sup>1</sup> adjusted for age sex, baseline response-efficacy and baseline fear, <sup>2</sup> adjusted for age, sex baseline self-efficacy and baseline fear, <sup>3</sup> adjusted for age, sex baseline self-efficacy and baseline response efficacy

## Discussion

In this study we found that fear significantly decreases during three months after TIA or ischemic stroke. Patients with TIA or ischemic stroke have high self-efficacy and response efficacy scores for health-related behavior change and these do not vary over time. This suggests that confidence in changing health behavior capacities and the believe that this change can prevent a new stroke are still high at three months. However, fear decreased after three months suggesting that the best time to start the intervention may be directly after the stroke or TIA and at least within three months.

To the best of our knowledge, this is the first study that focusses on changes in determinants of health-related behavior change after TIA or ischemic stroke. Self-efficacy has been studied before in patients with vascular disease (coronary heart disease, cerebrovascular disease or peripheral artery disease).<sup>[23, 25]</sup> In those studies, comparably high self-efficacy levels were found, but the self-efficacy was not monitored over time. Response efficacy for behavior change has not been described in patients with TIA or ischemic stroke before. Fear seems moderate (with a median of 16 on a scale of 32) and decreased strongly within 3 months after stroke or TIA. Fear started to decrease after six weeks. During this period, patients often undergo additional examinations to assess the underlying etiology at different medical specialists. This might lead to uncertainty and fear. Possibly patients also adopt to the uncertainty, which lowers the fear. We could not compare our findings with those of others as fear in relation to behavior change has not been studied quantitatively or in patients with TIA or stroke before. Fear of a recurrent stroke has been found in several other studies,<sup>[28-30]</sup> and this can possibly be used as an opportunity to motivate patients to change their health-related behavior in order to reduce risk of recurrence.<sup>[21]</sup> In two small studies with stroke patients fear was mentioned by patients as a motivating factor to change health behavior.<sup>[10, 28]</sup> Previous studies in patients with coronary artery syndrome have shown that the majority of patients who quit smoking successfully stopped immediately after the event.<sup>[31]</sup> Perceived feeling of a life-threatening disease seems to play a role in this process.<sup>[32]</sup> The European Society of Cardiology (ESC) guidelines recommend to seize this opportunity by addressing the issue of smoking before discharge.<sup>[33]</sup> These guidelines also recommend that support for cessation of smoking is initiated for all smokers during hospital admission and is continued for a prolonged period after discharge. Although there is no evidence for this approach in stroke patients, it seems reasonable to assume that this advice can also be effective after ischemic stroke or TIA.

Strengths of our study are that it is the first to focus on determinants of health behavior change after TIA or ischemic stroke over time. Also, we collected detailed information

about potential determinants such as difference between smokers and non-smokers. This study has also some limitations. First, we studied patients for a relatively short period of time. Patients are often rehabilitating longer than three months, which can cause further changes over time. Second, not all patients completed questionnaires at six weeks (n=35). Furthermore, social desirability bias during questionnaire completion may also have played a role as self-efficacy is high in these patients given our earlier study that showed that most patients do not actually change their behavior, due to the intention-behavior gap.<sup>[11, 30, 34]</sup>

In summary, at present it is unclear how and at which moment patients can be best supported in health-related behavior change after TIA or ischemic stroke. Fear, self-efficacy and response-efficacy play a role in this behavior change process. We found that response efficacy and self-efficacy remain high after three months, and fear decreased significantly after six weeks. Therefore, the optimal timing of supporting patients in health-related behavior change after TIA or ischemic stroke seems to be directly after the stroke or TIA.

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# PART

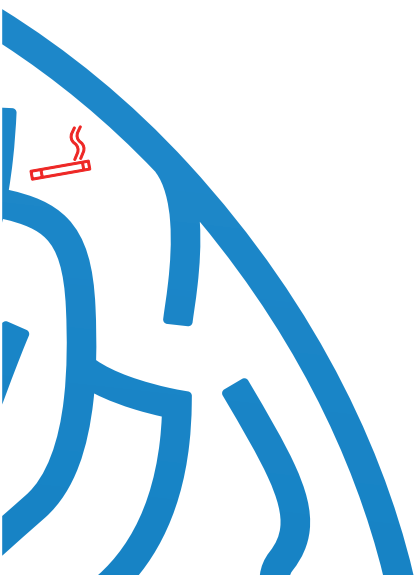
# 2





# Supporting patients in health-related behavior change after TIA or minor ischemic stroke

- 2.1 Health education in patients with recent stroke or transient ischemic attack; a comprehensive review
- 2.2 Motivational interviewing to support lifestyle behavior change after TIA or minor ischemic stroke at a nurse-led outpatient clinic



# Chapter

# 2.1



# Health education in patients with a recent stroke or transient ischemic attack: a comprehensive review

L. Maasland

D. Brouwer-Goossensen

H.M. den Hertog

P.J. Koudstaal

D.W.J. Dippel



**ABSTRACT**

Health education aims at the acquisition of skills and attitudes to modify behavior that influences health, leads to a modification of risk factors and ultimately to a decrease in disability and case fatality from stroke. Health education is an underdeveloped but important aspect of stroke care. Health education could promote compliance and healthy behavior, improve patients' understanding of their health status and treatment options and facilitate communication. We reviewed the effect of health education in stroke and transient ischemic attack patients, aiming at feasibility, effectiveness at the level of knowledge, attitude and skills, health behavior changes and stroke outcome. We also describe the current status of health education for patients with recent coronary artery disease and public health education in stroke. Basic knowledge of stroke and transient ischemic attack patients of their disease and associated risk factors is not sufficient. This is also observed in patients with coronary artery disease and in the general population. A beneficial effect of health education in stroke and transient ischemic attack patients on health behavior, risk reduction or stroke outcome has not been proven. Trials in patients with coronary artery disease, however, have shown that health education could result in a change of lifestyle. No specific method is superior, although the individualized, repetitive and active methods appear more successful. More intervention studies of health education in stroke and transient ischemic attack patients are needed. Future trials should be large, have a long follow-up, should use an intensive and repetitive approach and involve patients' relatives to induce and maintain a healthy lifestyle.

*Published in International Journal of Stroke, Feb 2011*

## Introduction

Implementation of preventive treatments and reduction of risk factor exposure at the population level has contributed to a significant reduction of the worldwide age- and gender specific stroke incidence over the past four decades.<sup>[1, 2]</sup> In the last 20-years, we have seen many improvements in acute stroke treatment modalities as well, including new medications, such as alteplase for intravenous thrombolysis<sup>[3]</sup> and organized multidisciplinary stroke units.<sup>[4]</sup> These treatment modalities aim to decrease stroke case fatality and disability. Despite these efforts and achievements, the absolute number of patients with stroke increases, because of the age increase in western populations. As a consequence, the population risk of recurrent vascular events and vascular dementia after transient ischemic attack (TIA) and stroke is increasing considerably, despite successful efforts to decrease the risk of individual patients with stroke, through preventive treatment.<sup>[5]</sup> Therefore, secondary prevention is an important part of stroke care. An important target for improvement of secondary prevention may be patient awareness of risk factors for stroke and behavior towards modification of risk factors. Health education (HE) is aimed at acquisition of skills and attitudes to change behaviors that influence health, and lead to a modification of risk factors, and to a decrease in disability and case fatality from stroke (Fig. 1). The effect of HE on the desired outcome is influenced by many factors that may be related to the individual patients, their knowledge and skills, their social environment, i.e. family and friends and the accessibility and quality of the healthcare system. The Helsingborg Declaration of 2006 stated that one of the core indicators for the assessment of quality of care is the proportion of patients given adequate advice about a healthy lifestyle.<sup>[6]</sup> However, HE is still an underdeveloped aspect of stroke care. It is not an accepted part of the secondary prevention programme in clinical practice. Although presently only a few international guidelines provide recommendations for HE in stroke and TIA patients<sup>[4]</sup>, the number of guidelines that focus on reduction of vascular risk by education and behavioral change is increasing.<sup>[4]</sup> In many patients, risk factors are not reduced to an optimal compliance with medical regimes<sup>[7]</sup> and by suboptimal health behavior with regard to diet and physical activity. We estimated the effect of changes in modifiable risk factors from typical to optimal, on the risk of new vascular events in patients with a recent TIA or stroke (Table 1).

**Table 1:** The estimated relative risk reduction on modifiable risk factors by health education for major vascular events in patients with TIA or ischemic stroke. Data from cohort studies or RCT's in patients with a recent TIA or ischemic stroke

Risk factor	Typical value in a stroke or TIA patient	Optimal value	Difference	Estimated relative risk reduction <sup>1</sup>	Source
BMI (kg/m <sup>2</sup> ) <sup>3</sup>	28	22	6	30%	Cohort studies (82, 83)
Smoking behavior (nr/day)	10	0	10	22%	Cohort studies (82, 83)
Cholesterol (mmol/l)	5.9	4.5	1.4	25-33% <sup>2</sup>	RCT <sup>4</sup> (84, 85)
LDL cholesterol (mml/l)	3.4	2.5	1.0	25-33% <sup>2</sup>	RCT <sup>4</sup> (84,85)
Blood pressure (mmHg)	130/80	120/75	10/5	25%	RCT <sup>4</sup> (86)
Physical activity (minutes/day)	<10	>30	>20	21%	Cohort studies (82, 83)

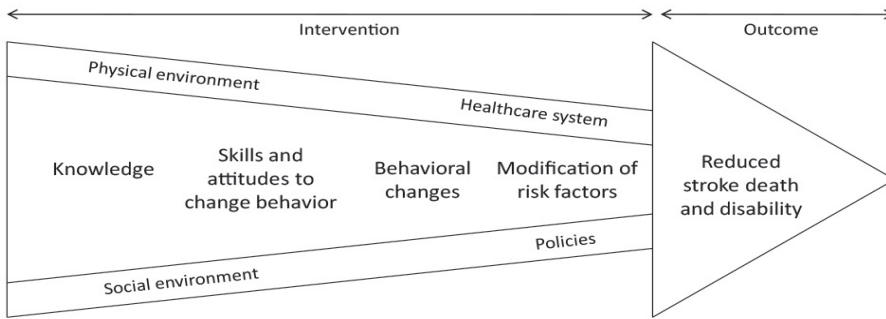
<sup>1</sup>Not adjusted for the other risk factors <sup>2</sup>if the compliance for statins is optimal <sup>3</sup>Body Mass Index

<sup>4</sup>Randomized controlled trial

The estimated relative risk reduction that can be achieved by adequate HE on top of the standard medical treatment ranges from 21% to 30% per separate risk factor. One has to take into account that this is a theoretical maximal effect. Moreover, there will be interaction between the risk factors; for example, reducing weight by increasing physical activity will also reduce the blood pressure. However, the effect of adequate HE can still be considerable. Health education is important for a number of reasons.<sup>[8]</sup> First, with the current regime of medication, like antiplatelet drugs, antidiabetica, lipid-lowering and antihypertensive drugs, physicians try to reduce the risk of a recurrent vascular event in stroke and TIA patients. Compliance with the pharmacological therapy is essential for the effectiveness of secondary prevention, but this is not optimal in stroke and TIA patients.<sup>[9]</sup> Health education could improve risk reduction by promoting compliance and healthy behavior. Second, it aims to improve patients and caregivers' understanding of their health status and treatment options. Third, HE should facilitate interactive communication between health provider and patient, and enhance patient participation in continuing care. Fourth, HE is considered necessary for prevention, because it is assumed that the more people know about their disease and associated risk factors, the more they could be willing to change their behavior in order to reduce the risk of future events. However, although patients with stroke and TIA already have had at least one vascular event, this does not automatically result in changes in health behavior to reduce their risk of a recurrent vascular event. Health education in stroke and TIA patients needs special consideration, because these patients have a few disadvantages in comparison with other vascular patients. They are generally older; patients with stroke are on average 5–10-years older than patients with acute coronary syndrome at the time of their event.<sup>[10, 11]</sup> Disability

or handicaps after stroke often result in increased needs of personal care and training at home or in a rehabilitation facility. Physical handicaps like even a mild paresis or language disorder as a consequence of stroke make it difficult to induce physical behavioral changes. Cognitive impairment after stroke may reduce the patient's ability to understand, retain and apply information provided through HE. Stroke and TIA patients and their partners generally wish to be informed about all aspects of their disease. Although information is provided to patients in hospital or after discharge, the patients' quest for information often cannot be met. A review indicated that patients and family are often dissatisfied with the content and quality of the provided stroke information about the causes, consequences and secondary preventive measures of stroke.<sup>[12]</sup> The HE for patients with stroke and TIA may fulfill information needs at least at three different levels. On the first level, patients wish to be informed about the manifestations and nature of their disease. On the second, patients need information about short- and long-term prognosis, including rehabilitation options. On the third level comes the need for HE focused on risk factor management and prevention of recurrent vascular events, which is more often a doctor's concern than a patient's need. During their disease, stroke and TIA patients experience different phases. The coping strategies are often aimed at actively adjusting circumstances to personal preferences and thus striving to maintain life as it was before the stroke (assimilative coping). Once the options of changing one's situation have been exhausted, coping changes into attempting to accept the consequences of the stroke by adjusting personal preferences and goals (accommodative coping).<sup>[13]</sup> In these different phases, different information is needed. It is likely that information concerning long-term risk and related health behavior will only meet fertile grounds when patients are in the phase of accommodative coping.

We have reviewed the status and effect of HE in patients with stroke and TIA on different targets as indicated in Fig. 1. We will first focus on studies of HE in stroke and TIA patients, aiming at feasibility, and effectiveness at the level of knowledge, attitude and skills, health behavior changes and stroke outcome. Progress in affiliated health domains, such as coronary artery disease (CAD), may help and inspire the development of HE in stroke and TIA patients. Second, we will describe the current status of HE for patients with recent CAD and we will summarize what is known about effective and feasible approaches to public HE in stroke.



Based on Carleton, R. A. et al. *Circulation* 1996;93:1768-1772

**Figure 1.** The steps and influences in the process of health education aiming at reduction of case fatality and disability from stroke

## Health education in stroke and TIA patients

### *Knowledge*

Many studies evaluated TIA and stroke patients' knowledge about etiology, warning signs and risk factors of their own disease.<sup>[14–18]</sup> The proportion of patients who are able to mention at least one warning sign varied between 39% and 93%.<sup>[14, 15, 17, 18]</sup> Hemiparesis was the most commonly cited warning sign.<sup>[14, 15]</sup> A variable proportion of stroke patients, 38–98%, was able to name at least one major risk factor.<sup>[14, 15, 17]</sup> This proportion depended on the type of question: open-ended or multiple choice. The latter resulted in the highest proportions. The most commonly mentioned vascular risk factors were hypertension, hypercholesterolemia and smoking.<sup>[14, 17, 19]</sup> Only a quarter to half of the stroke patients could mention the brain as an affected organ.<sup>[14–16]</sup> Most studies investigated the knowledge of stroke patients in the acute phase. In this stage, patients may not have received an appreciable amount of information yet. Therefore, the knowledge of stroke and TIA patients in the acute phase would be limited and not be very different of knowledge in the general population. The HE to stroke patients can be provided by different persons; a general practitioner, a stroke nurse specialist or a neurologist. No studies have compared the quality and effect of HE provided by different persons. There are many ways by which HE can be provided, both actively and passively. Examples of passive methods are booklets, a computer programme and computer-generated individualized written information. Active methods are information presented to a group or individual by, for example, a multidisciplinary team including a specialist stroke nurse, by means of presentations and interactive sessions. Few randomized controlled trials investigated the effect of



an intervention on the knowledge of stroke and TIA patients compared with standard care only. In a Cochrane review <sup>[20]</sup>, data were available for 536 of 770 participants from six trials.<sup>[21–26]</sup> Knowledge assessment of warning signs and risk factors varied between one-week and six-months. Overall, patients in the intervention groups had significantly more knowledge of stroke than those in the control groups. The magnitude of effect between passive and active information and the effect of individual tailored information was not different between the groups.

### *Attitude and skills*

Patients with acute stroke often experience a significant delay in reaching the hospital. This delay has three components: appraisal delay, the time from noticing a symptom to deciding one is ill; illness delay, the time from onset of symptoms to seeking professional help; and utilization delay, time from seeking professional care to arrival at the hospital.<sup>[27]</sup> Especially the appraisal and illness delay are patient dependent. Data about appraisal delay in stroke patients are limited, but studies showed that a history of stroke contributes to heightened awareness and recognition of stroke symptoms.<sup>[18, 28]</sup> Data about the illness delay, the time from onset of symptoms to seeking help, are conflicting. Some studies showed that patients who knew they had a stroke did not promptly seek medical attention. Even when stroke symptoms were correctly recognized, most patients who delayed their call for help, interpreted their symptoms as ‘not serious’.<sup>[18, 29]</sup> Other observational studies suggest that if patients realize that they are having a stroke or have symptoms comparable with a previous experience, they seek medical treatment sooner.<sup>[17, 28]</sup> Studies reporting interventions aimed at changes in attitudes towards risk factors for stroke and TIA are not available. Studies have focused on risk factor changes and compliance with lifestyle advice, the next step in the process of HE aiming to reduce stroke death and disability (Fig. 1).

### *Health behavior and risk factor modification*

A well-known problem at the behavioral level is the noncompliance with lifestyle advice. Vascular risk factors are negatively influenced by unhealthy lifestyles leading to obesity and an increased risk of hypertension, hypercholesterolemia and diabetes mellitus. Studies investigating the effect of HE on behavioral changes and risk factor modification in stroke and TIA patients are limited. We performed a small randomized controlled study with passive information provision to TIA and stroke patients provided by physicians vs. a combination of an individualized multimedia computer programme with physician support. We found no statistically significant differences between the two groups at three-months with regard to compliance with lifestyle recommendations<sup>[21]</sup>. Two trials showed there was no evidence of an effect of active information on the modification of health behaviors or risk reduction.<sup>[24, 30]</sup> The first trial investigated a

1-h small group educational session followed by six 1-h sessions after discharge.<sup>[24]</sup> A second study, with 205 stroke and TIA patients, evaluated the effect of additional input from the stroke nurse vs. advice provided by medical staff. The stroke nurse reviewed patients at monthly intervals for approximately three-months.<sup>[30]</sup> Another randomized controlled trial assessed whether extra care of a stroke nurse specialist could be beneficial in terms of the cardiovascular risk profile.<sup>[31]</sup> In addition to a vascular screening and prevention programme, the stroke nurse specialist promoted the self-management of risk factors. Selfmanagement refers to the individual's ability to manage both physical and psychosocial consequences including lifestyle changes inherent to living with a chronic condition. In self management, attention can be given to what is important and motivational to the individual patient.<sup>[32]</sup> Two hundred and thirty-six patients with manifestations of a vascular disease and with two or more modifiable vascular risk factors were pre-randomized according to the Zelen design to receive treatment by a nurse practitioner plus usual care or usual care alone. In the Zelen design participants are randomly allocated before seeking consent.<sup>[33]</sup> Participants allocated to the intervention group are then approached and offered the intervention, which they can decline or accept. Sixty-one patients (25%) refused to participate. This may have led to the selection of more motivated patients in the intervention group, and therefore, larger effects. After one-year, risk factors were assessed again. The primary endpoint was achievement of treatment goals for blood pressure, lipid, glucose and homocysteine levels, body mass index (BMI) and smoking. Treatment delivered by nurse practitioners resulted in a significantly better management of blood pressure, cholesterol and BMI than usual care alone after one-year.<sup>[31]</sup> The PROTECT cohort study systematically implemented, at the time of TIA or ischemic stroke, eight medication/behavioral secondary prevention measures known to improve outcome.<sup>[34]</sup> Medication goals were initiation of an antithrombotic, a statin, an angiotensin-converting enzyme inhibitor and a thiazide diuretic. The four behavioral interventions were smoking cessation counselling, exercise counseling, diet counselling and education about personal stroke risk factors and the need to call 911 if new stroke symptoms would occur. Endpoints were the proportion of individuals compliant with medical and lifestyle modification interventions after three-months and the frequency of recurrent vascular events. Adherence rates in patients were 100% for antithrombotics, 99% for statins, 92% for angiotensin-converting enzyme inhibitors and 80% for thiazide diuretics. Adherence to diet and exercise guidelines were 78% and 70%, respectively. Of the 24 smokers, 20 permanently stopped (83%). The authors from this uncontrolled study concluded that the increase in treatment adherence was associated with a favorable clinical event rate, with substantially fewer recurrent vascular events within the PROTECT cohort of individuals compared with results from other three-month hospitalization cohort studies.<sup>[35]</sup>

### *Outcome*

If information about stroke is not adequately provided to or received by stroke patients, this is likely to affect their compliance with secondary prevention and long-term outcome.<sup>[36]</sup> The direct effect of HE on compliance of lifestyle recommendations and consequently on outcome is not easy to measure. The chain of events leading from HE through changes in attitude and behavior to outcome is long, and the effect of interventions is dampened because of the many links in this chain. Outcome is a broadly defined item, which includes case fatality, recurrent vascular events, disability, anxiety or depression and quality of life. Moreover, outcome is influenced by many other factors, like healthcare system, social and physical environment (Fig. 1). Only a few trials are available of the effect of HE on outcome. In a Cochrane review<sup>[20]</sup>, interventions to deliver HE did not reduce lethality in patients with a recent TIA or stroke, compared with standard management (OR 0.82, 95% CI 0.56–1.21). The intervention consisted of group sessions, educational programmes, stroke nurse, booklets or individualized information delivered by computers. The review showed that HE did not affect the occurrence of anxiety (data from 681 participants in six trials), and depression (data from 956 participants in eight trials).<sup>[20]</sup> Three studies investigated the effect of a nurse-led support or education programme for stroke patients and their caregivers or spouses. No effects were found on quality of life, well-being<sup>[37]</sup> or depression<sup>[38]</sup> and small effects (in subgroup analyses) on social activities.<sup>[39]</sup> In one trial in which patients were visited at home, perception of health increased and emotional reactions and social isolation decreased significantly.<sup>[38]</sup>

## **Public stroke knowledge and education**

### *Knowledge*

It is well known that there are deficiencies in public knowledge of risk factors for stroke and of stroke warning signs. Moreover, in many countries the public awareness of acute stroke as a disabling, life-threatening disease, requiring prompt treatment, is far from optimal.<sup>[15, 40–55]</sup> The proportion of individuals able to mention a single warning sign for stroke varied from 40% to 70%.<sup>[56]</sup> In studies investigating knowledge of risk factors, at least 20% of the people could not correctly mention at least one risk factor.<sup>[17, 42, 44, 50, 57]</sup> The proportion of those who identified at least two risk factors was low, and ranged from 25% to 62%.<sup>[56]</sup> Hypertension was the most frequently recalled risk factor, followed by smoking. The most frequently noted sources of stroke knowledge were friends, family and mass media. Less commonly, physicians and hospital personnel were cited as sources.<sup>[41, 42, 50, 57]</sup> There is some evidence that those who are most at risk, the elderly, are the ones with the lowest level of knowledge. The effect of public educational campaigns aimed at improvement of stroke knowledge is variable.<sup>[51, 55, 58, 59]</sup> Producing long-term change

in public knowledge and behavior is possible<sup>[60]</sup> but difficult.<sup>[37, 60, 61]</sup> A study performed in the United States found that public knowledge of stroke risk factors did not substantially improve between 2000 and 2005 despite numerous national stroke public awareness campaigns.<sup>[62]</sup> An explanation for the failure of some public campaigns could be that they have neither been targeted to the proper audience nor tested for efficacy before widespread implementation. However, the mass-media campaign in the Netherlands, consisting of television and radio advertisements, combined with flyers distributed personally by volunteers at every household door, which started in 2005 with repeated advertisements till 2008, has improved knowledge about warning signs, i.e. the Face–Arm–Speech–Time test and care-seeking intention.<sup>[63]</sup> The number of respondents who could name at least one correct warning sign of stroke increased from 70% at baseline to 89% in 2008.

### *Attitude and skills*

Studies indicated that recognition of stroke is not sufficient to prompt stroke victims in the general population to call the national emergency number.<sup>[51, 64]</sup> One study found<sup>[65]</sup> that people who knew that stroke was a serious and treatable disease, were about twice as likely to call the emergency number. Calling the national emergency number was not driven by knowledge of risk factors and warning signs. Previous studies found that delay in seeking medical attention after stroke onset is the most frequent reason for low rates of thrombolysis for acute ischemic stroke.<sup>[66]</sup>

### *Health behavior and risk factor modification*

There are no studies available on the effect of HE on the public and the effect of risk factor modification concerning stroke.

## **Health education in patients with CAD**

Coronary artery disease is a significant public health problem in the developed world with high case fatality. The CAD caused about one of every five deaths in the United States in 2005.<sup>[59, 67]</sup> The CAD and stroke share many aspects such as the need of risk factor management and lifestyle change, of acute treatment and of treatment with antiplatelets or other preventive treatment. Given these similarities, the state of the art of HE for cardiovascular patients is of great interest.

### *Knowledge*

In contrast to studies in stroke, only a few studies assessed knowledge of disease, symptoms and risk factors in patients with an acute coronary syndrome.<sup>[68–70]</sup> All studies indicated low levels of knowledge of the participants. Short individual teaching by a nurse

and counselling intervention resulted in improved knowledge of CAD.<sup>[71, 72]</sup> A review of five studies investigating computer-software for education of patients with coronary heart disease demonstrated their effectiveness in increasing knowledge. The increased knowledge was demonstrated in patients who used the educational software immediately after the procedure. Only two of the five studies reported knowledge after six-months, with a large effect, using Cohen's delta as effect size measure.<sup>[73]</sup> Loss to follow-up varied from 12% to 33%.<sup>[74]</sup>

### *Attitude and skills*

Similar to stroke patients, it is important for patients to have knowledge of warning signs, so that they can quickly identify symptoms of acute coronary syndrome and take prompt action to seek care. Reperfusion therapy with either percutaneous coronary intervention or fibrinolytic drugs leads to lower case fatality and fewer complications. The case fatality of acute myocardial infarction is largely dependent on the time between symptom onset and reperfusion.<sup>[75]</sup> The main reasons for delay were the patients' perception that the symptoms might pass, because the symptoms were either not severe, or because the patient thought that the symptoms were caused by a different illness.<sup>[76]</sup> Some studies found that better awareness of CAD symptoms was associated with shorter prehospital delay times<sup>[71, 72]</sup> but others did not.<sup>[77, 78]</sup> The Rapid Early Action Coronary Treatment trial, in which members of the community received education through the mass media and one-on-one approach from their local healthcare providers, showed limited success.<sup>[77]</sup> Despite an 18-month exposure to the intervention, time from symptom onset to hospital arrival for patients with chest pain did not change significantly, although appropriate use of medical emergency facilities was more frequently observed in the intervention communities. In another trial, participants (n53522) with documented CAD were randomized to experimental (n51777) or control (n51745) groups. Patients in the experimental groups received education and counselling about CAD symptoms and required actions. The education and counselling intervention did not lead to reduced prehospital delay or increased ambulance use.<sup>[78]</sup> However, short individual teaching and counselling intervention by a nurse resulted in improved knowledge of CAD and also in more appropriate responses to symptoms in people with a myocardial infarction sustained to 12-months.<sup>[71, 72]</sup>

### **Health behavior and risk factor modification**

The EUROASPIRE III survey showed that large numbers of CAD patients do not achieve the desired lifestyle, risk factor modification and therapeutic targets for cardiovascular disease prevention.<sup>[79]</sup> Therefore, intervention trials with integrated HE are designed to achieve targets as defined in the prevention guidelines in routine clinical practice. In one trial, 3241 patients with recent myocardial infarction were randomized to a three-year

multifactorial educational and behavioral programme or usual care.<sup>[80]</sup> Comprehensive cardiac rehabilitation sessions with one-to-one support were held monthly from month 1 to month 6, then every six-months for three years. Each session consisted of 30 min of supervised aerobic exercise, plus lifestyle and risk factor counselling lasting at least 1 h and reinforcement of preventive interventions lasting approximately 30 min. In this way, every patient received in total 15 h of counselling in three-years. To improve adherence to lifestyle modification and help patients adopt a positive role in the care of their own health, a booklet explaining how to deal with exercise, diet, smoking cessation and stress management was distributed. The mutual support of family members was encouraged in ad hoc meetings together with the patients to make correct lifestyle habits more likely to be maintained in the long run. Compared with the usual care, the intensive intervention did not decrease the primary combined end point of fatal and nonfatal vascular events significantly, but intervention decreased several secondary end points like cardiovascular mortality plus nonfatal MI and stroke and induced a considerable improvement in lifestyle habits. In the EUROACTION study<sup>[81]</sup>, a cluster-randomized, controlled trial in eight European countries, a nurse-coordinated multidisciplinary, family-based preventive cardiology programme vs. standard care was investigated. More than 3000 patients with CAD and their partners were encouraged to achieve a healthy lifestyle with support from their families, other people attending the programme, and the health professionals – i.e., hospital nurses, dietitians and physiotherapists – who used stages of change and motivational interviews. Nurses coordinated a programme of eight workshops – one a week – for coronary heart disease; cardiovascular risks – i.e. lifestyle and risk factor control; cardioprotective treatments; and return to work and leisure. After completion of the 16-week hospital programme, patients and their partners were reassessed for lifestyle, risk factors and therapeutic management, and results were sent to each individual's own family doctor. All patients and their partners were invited back for reassessment at one-year. Endpoints were smoking cessation, blood pressure <140/90mmHg, LDL <3 mmol/l, BMI <25 kg/m<sup>2</sup>, physical activity ≥30 min more than four times per week, intake of more than 400 g a day of fruits and vegetables and < 10% of total energy supplied by saturated fat. This study did not include vascular events as endpoints. The intervention group had significantly lower blood pressures, made significantly healthier food choices and became physically more active. This effect was mainly attributed to lifestyle change supported by families.

## Improving health education in stroke and TIA patients

Basic knowledge of stroke and TIA patients of their disease and associated risk factors is not sufficient. This is observed in patients with CAD and in the general population as well. The preventive effect on the occurrence of major vascular events of interventions focusing on improvement of stroke knowledge has not been conclusively demonstrated, but a tendency towards a positive effect on knowledge of warning signs and vascular risk factors in public and patients can be observed. No specific method of HE is superior, although the individual and repetitive, active methods seem more successful. There is no conclusive effect of active information aimed at stroke patients on the modification of health behavior, risk reduction or outcome measurements. Trials in patients with CAD have provided promising results.<sup>[80,81]</sup> Two randomized trials showed considerable improvement in lifestyle. Compared with trials in stroke patients, these trials included more patients, involved partners more actively and used intensive and repetitive ways of HE with active participation of the patients. Moreover, they had a longer follow-up period than trials in stroke patients. Knowledge is a necessary factor for inducing change, but the process of modification of risk factors is a multistaged and complex one, requiring the right attitude, motivation and capacity to change behavior. HE provides a different approach to the reduction of stroke death and disability. Moreover, HE may be used to improve medication compliance. The first step in modification of risk factor behavior is improvement of the quality of the provided information. The HE provided by physicians is often based upon what health professionals think patients should know. Reports have demonstrated that patients are dissatisfied with the content of stroke information.<sup>[12]</sup> The question is whether this is only due to quality of the information or to the mental and emotional status of the patient, who may have difficulty in retaining information. Three levels should be discerned when one provides HE to stroke patients, HE about nature and manifestations of stroke, about prognosis and rehabilitation and about risk factor management and prevention. It is likely that patients are generally more interested in their prognosis and rehabilitation possibilities, and physicians in risk factor modulation and lifestyle advices. Many educational programmes are hospital based, the time when patients are least able to retain information. HE about stroke should start during the acute phase, and should be continued after discharge, and should preferably be provided by the same persons. Interactive stroke-specific software may offer an opportunity, with possibility of accessibility, repetition, but with the disadvantage of missing personal information. Stroke specialist nurses or nurse practitioners may play an important role in providing information in HE to TIA and stroke patients. In conclusion, the information should address the patients' issues, needs and concerns. The information should be patientcentred, interactive, personalized, flexible and repetitive. It should create opportunities to apply the new knowledge that leads to attitude changes. HE is a time-consuming way of preventive medicine for stroke physicians. Studies

showed that extra care of a stroke nurse specialist could be beneficial in terms of the cardiovascular risk profile.<sup>[31, 81]</sup> These studies showed a positive effect of nurse practitioners who used stages of change or self-management techniques as part of vascular preventive programme. <sup>[31, 81]</sup> Stroke nurse specialists could combine vascular care coordination with promoting selfmanagement or another cognitive behavioral approaches to induce healthy lifestyle. They could also pay attention to patients' relatives, who play an important role in inducing and promoting healthy lifestyle behaviors in patients.<sup>[81]</sup> HE is a time-consuming, but potentially effective way of preventing vascular events after TIA or stroke. The HE should offer more than telling patients general facts on vascular disease. It should not only focus on improving knowledge but also on attitude and risk factor behavior, should take the stage of motivation or willingness to change lifestyle into account and demand active participation of patients. A stroke nurse specialist could play an important role in HE. The experience of cardiologists, who have shown that HE results in a change of lifestyle, is important also for neurologists. Nevertheless, the effect of HE on the incidence of vascular events or on outcome after stroke remains to be demonstrated. Future trials investigating the effect of HE in stroke and TIA patients should be large, have a longer follow-up period, should use an intensive and repetitive manner of HE and involve patients' relatives to induce and maintain a healthy lifestyle.



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# Chapter

# 2.2



# Motivational interviewing in a nurse-led outpatient clinic to support lifestyle behavior change after admission to a stroke unit: a randomized controlled trial

D. Brouwer-Goossensen

M. Scheele

L. van Genugten

H.F. Lingsma

D.W.J. Dippel

P.J. Koudstaal

H.M. den Hertog



## ABSTRACT

### Background

Modification of health behavior is an important part of stroke risk management. However, the majority of people with cardiovascular disease fail to sustain lifestyle modification in the long-term. We aimed to evaluate the effectiveness of motivational interviewing to encourage lifestyle behavior changes after TIA or minor ischemic stroke.

### Methods

We performed a randomized controlled open label phase II trial with blinded endpoint assessment. The intervention consisted of three 15-minute visits in three months by a motivational interviewing trained nurse practitioner. Patients in the control group received standard consultation after one and three months by a nurse practitioner. Primary outcome was lifestyle behavior change, defined as smoking cessation and/or increased physical activity (30 minutes/day) and/or healthy diet improvement (5 points at the Food Frequency Questionnaire) at 6 months. We adjusted for age and sex with multivariable logistic regression.

### Results

Between January 2014 and February 2016, we included 136 patients (of whom 68 were assigned to the intervention group.) Twenty-five of 55 patients in the intervention group (45%) and 27 of 61 patients in the control group (44%) had changed their lifestyle at six months. We found no effect of motivational interviewing on lifestyle behavior change after six months (aOR 0.99; 95% CI 0.44-2.26).

### Conclusion

Our results do not support the effectiveness of motivational interviewing in supporting lifestyle behavior change after TIA or minor ischemic stroke. However, the overall lifestyle behavior change was high and might be explained by the key role of specialized nurses in both groups.

*Submitted*



## Background

After a ischemic stroke or TIA patients have an increased risk of recurrent stroke and cardiovascular events.<sup>[1,2]</sup> In addition to adequate treatment of risk factors like hypertension and hypercholesterolemia, many guidelines recommend lifestyle behavior change such as regular physical exercise, healthy diet, stop smoking and no excessive use of alcohol to reduce this risk.<sup>[3-5]</sup> In patients with coronary artery disease, the benefits of lifestyle management on vascular risk factors as well as the risk of vascular death and myocardial infarction have been demonstrated. However, the majority of people with cardiovascular disease fail to sustain lifestyle modification in the long-term.<sup>[6, 7]</sup> Therefore a lifestyle intervention supporting patients in changing health behavior could be an effective way to reduce stroke recurrence.

At present, only inconsistent data and data of varying quality are available on interventions to support patients in health-related behavior change after TIA or ischemic stroke.<sup>[8, 9]</sup> These interventions varied from personal education, exercise or lifestyle classes, motivational counselling (not specified), telephone support, home visits and interviews.<sup>[10]</sup> The heterogeneity in applied interventions with regards to content, intensity, behavior focused on and duration makes comparing complex. Follow-up rates are often low and patients experience physical barriers such as fatigue or pain, lack of knowledge and social support, and cognitive problems.<sup>[11-15]</sup>

Roger's revised Protection Motivation Theory (PMT)<sup>[16]</sup> describes socio-cognitive factors that play a role in individual's motivation to change or not to change health-related behavior. This theory assumes that behavior change is a consequence of behavioral intention to change.<sup>[17]</sup> One of the factors that plays an important role in this process is perceived self-efficacy. In our previous study<sup>[18]</sup> we found that self-efficacy (a person's confidence to carry out behavior necessary to reach a desired goal) was the strongest determinant of intention to stop smoking, increase physical activity and improve healthy diet. Self-efficacy has been found to be a powerful predictor of intention to change in other cardiovascular studies.<sup>[19-23]</sup> It has a direct effect on health-related behavior, is the strongest predictor of health-related behavior change<sup>[23, 24]</sup> and an important precondition for successful self-management.<sup>[21, 25]</sup> Hence increasing self-efficacy could be a way to support health-related behavior change in patients with TIA or ischemic stroke.

A promising method to support behavior change by increasing self-efficacy and self-management is motivational interviewing. Motivational interviewing is defined as a client-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence. It is designed to strengthen personal motivation for and

commitment to a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion.<sup>[26]</sup> It has been developed by Miller in 1983 to support people with alcohol abuse to stop drinking.<sup>[27]</sup> Empathy, open questions, reflective listening and emphasis on patients autonomy are the basic communication skills of motivational interviewing.<sup>[26]</sup> Motivational interviewing has been proven effective in adopting healthy lifestyle behavior for patients with chronic diseases as well as in patients with cardiovascular diseases,<sup>[14-17]</sup> in particular in supporting weight loss behaviors and reducing alcohol and tobacco intake.<sup>[28, 29]</sup> These effects occur when conversations were short and repeated<sup>[29]</sup> and may persist at least one year after counselling.<sup>[30]</sup> Motivational interviewing to support patients in health-related behavior change after TIA or stroke seems an attractive method as this form of support can be effective in short conversations, can be applied everywhere (including outside the hospital) and can be easily trained. Since follow-up rates are often low and many patients are already bothered by many appointments and obligations (like medication adherence) after their stroke these characteristics are very important. A recent study of 49 stroke patients, studied feasibility of motivational interviewing for low mood and showed that it is possible to train staff to deliver motivational interviewing and motivational interviewing sessions are acceptable for both patients as therapists.<sup>[31]</sup>

The effects of motivational interviewing on health-related behavior change after TIA or ischemic stroke are largely unknown.<sup>[32-34]</sup> A recent randomized controlled trial in 386 patients with minor stroke found no effect on blood pressure or cholesterol levels, but medication adherence was significantly higher.<sup>[35]</sup> Two small studies have shown promising effects of motivational interviewing on physical activity, dietary behavior,<sup>[36]</sup> blood pressure and self-efficacy after stroke<sup>[37]</sup> (a person's confidence to carry out behavior necessary to reach a desired goal).<sup>[24]</sup> However, the intensity of the intervention and duration of the conversations has not been well described. Therefore we aimed to assess whether motivational interviewing is an effective and feasible method to support lifestyle changes after a TIA or ischemic stroke.

## Methods

We conducted a randomized clinical trial with blinded outcome assessment. Patients were recruited in the first week after admission to the stroke unit or TIA outpatient clinic.

## Participants

Patients were eligible for inclusion if they were 18 years or older and had a clinical diagnosis of TIA, including amaurosis fugax, or minor ischemic stroke with a modified Rankin Scale score of 3 or less.<sup>[38]</sup> Patients were excluded if they were discharged to a nursing home,

were non Dutch-speaking or had severe aphasia. The trial was approved by national and local institutional review boards (trial number 3988107812) and written informed consent was obtained from all patients. Patients were included during admission or visit to the outpatient clinic.

## Intervention

Patients were randomly allocated to motivational interviewing or standard counselling. For this purpose, an independent trial assistant had concealed computer-generated allocation sequences in consecutively numbered, opaque, sealed envelopes. When a patient was included and given a (consecutive) trial number, the corresponding numbered envelope was opened, by which the patient was assigned to intervention or control group.

All patients received routine general lifestyle advice during admission or visit to the outpatient clinic including regular physical exercise (more than 30 minutes of moderate or intense activity every day), healthy diet, and advice to stop smoking as part of standard care at baseline by a neurologist. Patients in the intervention group received counselling by an experienced nurse practitioner at approximately four weeks, eight weeks and three months after inclusion. During these sessions of fifteen minutes, lifestyle behavior, motivation and opportunities for change were discussed. Patients were asked what behavior they would change if they changed their lifestyle and how they would approach this change. Previous attempts were discussed in which successes were highlighted. Open questions and complex reflections were used to enlarge ambivalence between intentions and action. When patients were in action phase questions were asked about method and planning of the change and when patients actually changed their behavior maintenance was discussed. Advice was only given with patients consent and emphasis was placed on the positive effects of change without reducing patients autonomy. The nurse practitioner delivering the intervention had completed two days basic and six days expert training in motivational interviewing. During the study the nurse practitioner was coached by a motivational interviewing certified trainer, mean Motivational Treatment Integrity score was 4.6 (out of five, the higher the score, the better the motivational interviewing skills).<sup>[39]</sup> Patients in the control group received consultation by another experienced, but not motivational interviewing trained nurse practitioner, who was part of the routine care, after approximately four weeks and three months after admission. During these sessions of fifteen minutes, lifestyle behavior and general lifestyle advice were discussed. All consultations were given at the same outpatient clinic, in the same room. Data were collected by a separate investigator in a different room than the consultation room, but the same room for patients in intervention or control group.

## Procedures

At baseline, we recorded clinical features of the TIA or ischemic stroke, demographic data, quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS, a 15-item scale with scores that range from 0 to 42 and higher values indicating greater severity),<sup>[40]</sup> vascular history and risk factors (including use of alcohol), body mass index, waist circumference and use of medication. Cholesterol levels, glucose levels and blood pressure were measured at baseline and 6 months thereafter. Follow up visits were scheduled at three months and 6 months after inclusion. The following questionnaires were completed during these visits:

- Actual smoking status was assessed with questions on current smoking status, how many years a patient had smoked, and average number of cigarettes smoked per day.
- Physical activity, measured with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire. Patients were asked to report activities performed for at least 10 minutes during the last 7 days, and time spent in physical activity performed across leisure time, work, domestic activities, and transport at each of 3 intensities: walking, moderate, and vigorous.<sup>[41]</sup> We used reported minutes of moderate and vigorous physical activity to calculate a total physical activity score of minutes a day. Cronbach's alpha was 0.79.
- Dietary behavior, evaluated with the short Food Frequency Questionnaire (FFQ). This 14-item scale is used to assess the intake of saturated fatty acids, unsaturated fatty acids, and fruits and vegetables over the week before the visit. An overall cardiovascular dietary score was calculated, ranging from -17 to +19, the higher the score, the more favorable the dietary pattern.<sup>[42]</sup> Cronbach's alpha was 0.71.
- Intention to change was assessed by means of a single item per behavior.<sup>[41]</sup> Patients were asked on a scale of 1 to 5, the likelihood that they would :
  - get 30 minutes of moderate to heavy daily physical activity in the next 3 months
  - decrease intake of unhealthy fats/ reduce their total energy intake in the next three months?
  - stop smoking within the next 3 months.

Higher scores indicate higher intention to change.

- Self-efficacy, measured with the self-efficacy scale, a 7-item scale with scores that range from 1 to 5. Higher values indicate more confidence to carry out the behavior necessary to reach the desired goal.<sup>[22, 43, 44]</sup> Questions are formulated as: I think I am able to quit smoking / choose healthy food/ care for enough physical activity. Cronbach's alpha was 0.84.

### **Outcome measures**

Primary outcome measure was lifestyle behavior change after 6 months, defined as smoking cessation and/or increase of physical activity of 30 minutes a day and/or increasing score of 5 points on the Food Frequency Questionnaire. These outcome measures were based on the food and exercise recommendations in the Netherlands.

Secondary outcome measures included change in self-efficacy and intention to change lifestyle behavior, change in weight, waist circumference, blood pressure, cholesterol and blood glucose after six months and feasibility of motivational interviewing on the nurse-led outpatient clinic.

A sample of 136 patients was expected to have a power of 80% to detect a difference in lifestyle behavior change (quitting smoking and/ or a 30-minute increase in exercise and/ or a 5-point increase in Food Frequency Questionnaire) between the intervention group and control group of 25% after 6 months assuming a significance level of  $\alpha = 0.05$  and a change in lifestyle behavior of 30% in the control group.

### **Statistical analysis**

Statistical analyses were performed with STATA 12.1 statistical package (Statacorp, College Station, Texas). Analyses were done by intention-to-treat principles. Differences in characteristics were analyzed with Chi2 tests (proportions), ttests and in case of unequally distributed data with Mann-Whitney U tests. Differences in primary and secondary outcomes between control and intervention group were compared with Chi2 tests and further analyzed by multivariable logistic or linear regression in which we adjusted for age, sex, baseline self-efficacy, baseline smoking status and history of TIA (because of unbalanced trial arms). Differences between primary outcomes in subgroups were analyzed with Chi2 tests. These subgroups contained patients with high self-efficacy scores (22 or higher based on median self-efficacy of 22) or low (<22) self-efficacy scores and patients who received all three counselling sessions and patients who had one or

two sessions (per protocol analysis). The data that support the findings of this study are available from the corresponding author upon request.

**Table 1:** Baseline characteristics ( N=136)

	Intervention n=68	Control n=68	p
Sex (male), n (%)	39 (57)	46 (68)	0.43
Age (years), mean (SD)	64 (13)	62 (14)	0.84
<i>Event characteristics:</i>			
Event type (TIA), n (%)	21 (31)	22 (32)	0.96 <sup>i</sup>
Stroke etiology (TOAST) <sup>1</sup> , n (%)			
Large vessel disease	15 (22)	10 (14)	0.20
Cardiac embolism	6 (9)	4 (6)	0.16
Small vessel disease	7 (10)	15 (22)	0.09
Other	2 (3)	6 (9)	0.17
Undetermined	38 (56)	33 (49)	0.85
NIHSS score <sup>2</sup> , median (IQ)	0 (0-1)	0 (0-2)	0.93
<i>Vascular history, n (%)</i>			
TIA	13 (20)	5 (7)	0.09
Ischemic stroke	10 (15)	11 (16)	0.90
Ischemic heart disease	18 (27)	16 (24)	0.89
Atrial fibrillation	3 (4)	4 (6)	0.77
Peripheral arterial disease	5 (7)	3 (4)	0.43
No vascular history	35 (51)	37 (54)	0.98
<i>Lifestyle:</i>			
Smoking, n(%)	10 (15)	18 (26)	0.09 <sup>j</sup>
Alcohol abuse, n (%)	10 (15)	6 (9)	0.29
Physical exercise <sup>3</sup> (min/day), median (IQ)	71 (29-174)	69 (24-150)	0.66
Physical exercise > 30 min a day n (%)	44 (73)	43 (68)	0.43
Overall dietscore <sup>4</sup> , median (IQ) from -17 to +19	1.0 (-2 -3)	1 (-1-2)	0.63
BMI (kg/m <sup>2</sup> ), mean (SD)	28 (4.8)	27 (5.2)	0.70
Overweight (BMI>25), n(%)	46 (74)	43 (65)	0.27

**Table 1:** Baseline characteristics ( N=136)

<i>Vascular risk factors:</i>			
Hypertension, n (%)	48 (72)	44 (65)	0.53
Systolic blood pressure (mmHg), mean (SD)	135 (19)	137 (18)	0.79
Diastolic blood pressure (mmHg), mean (SD)	76 (12)	79 (10)	0.06
Statin use, n (%)	62 (91)	59 (87)	0.16
LDL level (mmol/l), mean (SD)	3.4 (1.2)	2.9 (1.1)	0.06
Blood glucose level (mmol/l), mean (SD)	5.9 (1.4)	6.2 (2.6)	0.28
Diabetes Mellitus, n (%)	20 (29)	15 (22)	0.69
<i>Coping:</i>			
Self-efficacy <sup>5</sup> non smokers total, median (IQ) from 0-24	20 (16.5-23)	22 (18-23)	0.46
Self-efficacy smokers total, median (IQ) from 0-28	22 (16-26)	22.5 (17.5-25)	0.93
<i>Intention to change:</i>			
Intention to change physical activity, median (IQ) from 0-4	3.5 (2-4)	3 (2-4)	0.51
Intention to change dietary behavior, median (IQ) from 0-4	3 (2-4)	3 (2-4)	0.88
Intention to quit smoking, median (IQ) from 0-4	2 (0-4)	2 (1-4)	0.66

<sup>1</sup> Classification of subtype of acute ischemic stroke developed for the Trial of Org 10172 in Acute Stroke Treatment (TOAST).

<sup>2</sup> Quantification of stroke severity according to the National Institutes of Health stroke scale (NIHSS), a 15-item scale with scores that range from 0 to 42 and higher values indicating greater severity.

<sup>3</sup> Measured with the International Physical Activity Questionnaire short (IPAQ-S) questionnaire.

<sup>4</sup> Evaluated with the short Food Frequency Questionnaire (FFQ). The higher the score, the more favorable the dietary pattern.

<sup>5</sup> Self-efficacy, measured with the self-efficacy scale, a 9-item scale with scores that range from 1 to 5. Higher values indicate more confidence to carry out the behavior necessary to reach the desired goal.

**Table 2:** Behavior change after six months follow-up

	Control n (%)	Intervention n (%)	p	aOR <sup>2</sup> 95% CI)
Overall behavior change <sup>1</sup> (n=116)	27 (44)	25 (45)	0.95	0.99 ( 0.44-2.26)
Quit smoking (n=28)	4 (22)	2 (20)	0.62	1.77 (0.22-14.02)
More physical activity (n=95)	20 (43)	19 (40)	0.76	0.71 (0.29-1.76)
Healthy diet (n= 92)	6 (13)	5 (11)	0.87	0.70 (0.16-3.03)

<sup>1</sup> defined as smoking cessation and/or increase of physical activity of 30 minutes a day and/or increasing score of 5 points on the Food Frequency Questionnaire.

<sup>2</sup> adjusted for age ,sex, history of TIA, baseline self-efficacy and smoking status at baseline.

## Results

Hundred thirty-six patients were enrolled between January 2014 and February 2016 of whom 68 were assigned to the intervention group. Follow-up was completed in 92 patients (Figure 1). Two patients died, 4 patients had a recurrent severe ischemic stroke, and 21 patients refused follow-up, did not filled in the questionnaire during their appointment or did not respond on telephone calls or appointment invitations. The other 6 patients were excluded because of dementia, discharge to a nursing home or rehabilitation center, or being diagnosed as a stroke mimic. Baseline characteristics were well balanced (Table 1), except for history of TIA which was more common in the patients allocated to motivational interviewing, and smoking that occurred more often in the control group. In the total study population, mean age was 63 years (SD 14), 85 (63%) patients were male and 43 (32%) had a TIA. Patients had a moderately healthy lifestyle; median physical activity time was 71 minutes a day (IQ 26-150), Body Mass Index was 28 kg/m<sup>2</sup> (SD 5.01) and median diet score was 1 (IQR -1-3) at baseline. Sixteen patients (12%) used more alcohol than advised (more than 2 units a day for women and three units a day for men) and 28 patients (21%) were smokers. Twenty-five of 55 patients in the intervention group (45%) and 27 of 61 patients in the control group (44%) had changed their lifestyle at six months. We found no evidence for benefit of motivational interviewing on lifestyle behavior change after six months (Table 2, aOR 0.99; 95% CI 0.-2.26). In the per protocol analysis the effect of motivational interviewing was very much the same (Table 3, aOR 0.97; 95% CI 0.37-2.52 and data in supplemental file). Also there were no positive effects of motivational interviewing on reduction of waist, cholesterol levels and blood pressure (Table 4). Overall self-efficacy and self-efficacy for quitting smoking was improved in the intervention group, but this was not significant (aBeta 0.19; 95% CI – 0.07-0.46). Patients in the intervention group with low baseline self-efficacy scores stopped smoking more often than patients in the control group (Table 5). There were no differences in physical activity and dietary behavior between patients with high or low self-efficacy scores. More patients in the motivational interviewing group (50%) than in the control group (33%) quit smoking (p 0.39) at three months follow-up (data in supplemental file). This trend did not sustain after six months.

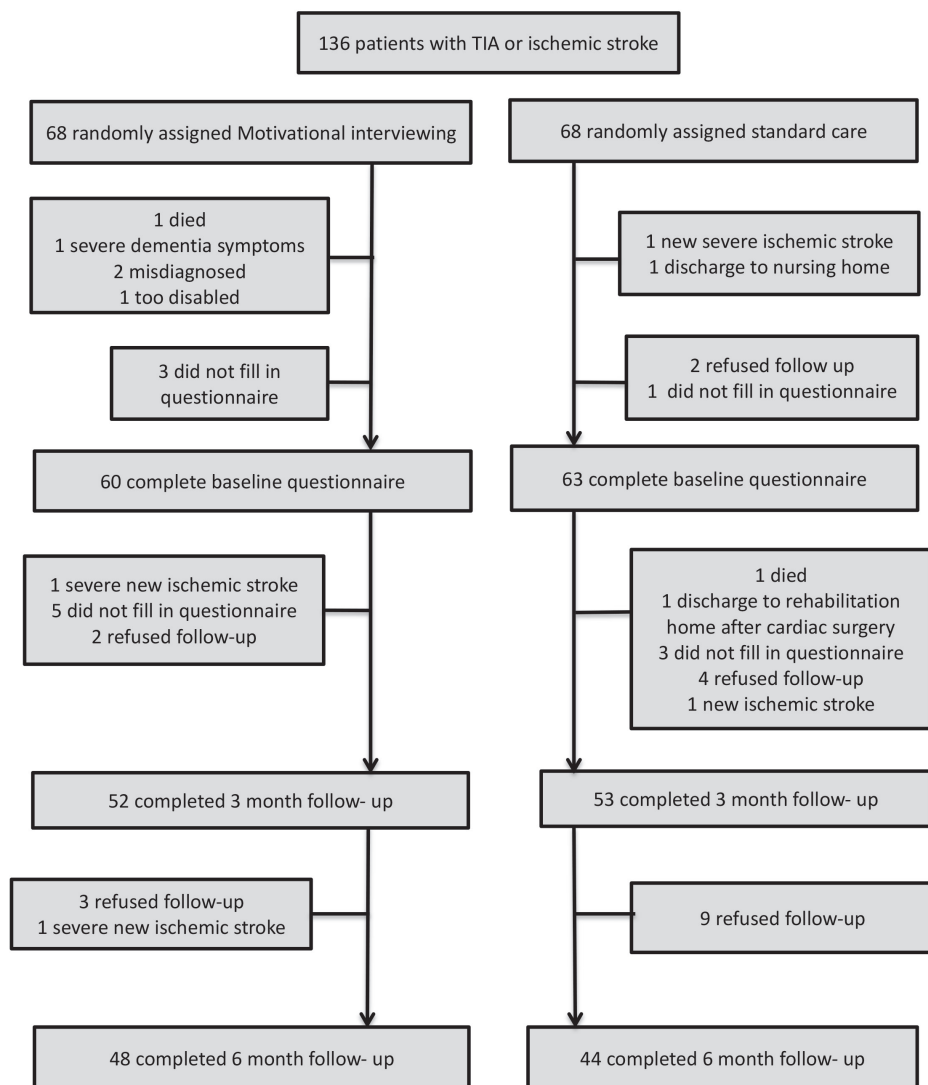
**Table 3:** Per protocol analysis for behavior change after six months follow-up

	Control n (%)	Intervention n (%)	p	aOR
Overall behavior change (n=95)	26 (43)	15 (43)	0.96	0.97 (0.37-2.52)
Quit smoking (n=24)	4 (22)	2 (33)	0.58	1.70 (0.18-16.30)
More physical activity (n=77)	19 (41)	10 (32)	0.41	0.61 (0.22-1.72)
Healthy diet (n=78)	6 (13)	4 (13)	0.71	0.72 (0.15-3.43)

<sup>†</sup> adjusted for age, sex, history of TIA, baseline self-efficacy and smoking status at baseline



**Figure 1.** Flow chart of inclusion and follow up of patients



**Table 4:** Change in secondary outcomes after six months follow-up

	Control	Intervention	p	aBeta (95% CI)
Waist circumference, mean (SD) (n=75)	2.42 (5.7)	1.41 (8.2)	0.53	-0.84 (-4.51-2.83)
Weight loss, mean (SD) (n=42)	-4.8 (2.5)	-4.18 (5.2)	0.67	-1.23 (-4.93-2.47)
Systolic blood pressure, mean (SD) (n= 92)	-8.8 (18)	-6.2 (17)	0.45	-2.07 (-7.66-3.53)
Diastolic blood pressure, mean (SD) (n=92)	-5.0 (11)	-3.5 (11)	0.51	-1.71 (-5.27-1.85)
Total cholesterol, mean (SD) (n= 89)	-0.80 (1.2)	-0.58 (1.2)	0.39	0.41 (0.03-0.80)
Glucose, mean (SD) (n=79)	-0.05 (3.0)	0.49 (1.6)	0.32	0.70 (-0.03-1.43)
Intention to change physical activity, median (IQ) (n= 88)	0.0 (0-1)	0 (0-1)	0.82	-0.19 (-0.84-0.44)
Intention to follow healthy diet, median (IQ) (n= 82)	0 (-1-1)	0 (0-1)	0.58	0.17 (-0.76-1.19)
Intention to quit smoking, median (IQ) (n= 6)	-1 (-1-0)	0 (-2-0)	1.00	0.43 (-1.91-2.79)
Self-efficacy overall, median (IQ) (n= 95)	3.7 (3-4)	3.7 (3-4)	0.09	0.19 (-0.07-0.46)
Self-efficacy smokers, median (IQ) (n= 14)	19 (17-23)	25.5 (19-28)	0.06	1.01 (-13.2-15.2)
Self-efficacy non smokers, median (IQ)( n= 81)	22 (19-24)	22 (21-23)	0.64	-0.58 (-2.33-1.15)

<sup>1</sup> adjusted for age ,sex, history of TIA, baseline self-efficacy and smoking status at baseline

**Table 5:** Behavior change after six months in patients with high or low self-efficacy

	Self-efficacy	Control n (%)	Intervention n (%)	p
Quit smoking (n= 11) (n= 14)	Low	0 (0)	2 (50)	0.04
	High	4 (44)	0 (20)	0.08
More physical activity (n= 45) (n= 41)	Low	10 (48)	7 (29)	0.20
	High	10 (48)	11 (55)	0.63
Healthy diet (n= 44) (n= 41)	Low	3 (15)	4 (17)	0.89
	High	3 (13)	1 (6)	0.42

## Discussion

Our results do not support the effectiveness of motivational interviewing in supporting lifestyle behavior change after TIA or minor ischemic stroke. The overall lifestyle behavior change in our study was high and might be explained by the key role of specialized nurses in both groups.

Only three published studies focused on the effects of motivational interviewing on health-related behavior after TIA or ischemic stroke. Two of these studies were small and showed promising effects on physical activity, dietary behavior, blood pressure and self-efficacy.<sup>[36, 37]</sup> In line with our results, a recent randomized controlled trial in 386 stroke patients found no effect on blood pressure or cholesterol levels, but medication adherence was significantly higher in the intervention group.<sup>[35]</sup> Usual care after discharge by a general practitioner or at a designated stroke clinic was supplemented with 4 face to face or telephone motivational interviewing sessions in 9 months. A recent review of motivational interviewing on lifestyle modification in patients with cardiovascular diseases showed that motivational interviewing was more effective than usual care on changing smoking habits and physical activity.<sup>[45]</sup> Motivational interviewing did not differ from usual care in changing dietary behavior.<sup>[45]</sup>

Although no overall effect of motivational interviewing on life style behavior change could be found in our study, there might be an effect on smoking behavior. After three months 50% of the patients in the intervention group stopped smoking compared to 33% in the control group (data in supplemental file). This trend did not sustain after six months. Earlier studies showed that motivational interviewing was particularly effective when conversations were short and repeated.<sup>[29]</sup> The conversations in our study were short but possibly not repeated often enough and as a consequence the effect of the intervention on smoking behavior did not sustain.

In this study, the number of patients that changed their lifestyle was high in both treatment groups. In our previous study with a similar study population, only 37% of the patients changed their lifestyle<sup>[18]</sup> in contrast to 44% in the control group of the present study. This might be explained by dedicated care of the nurses in both arms of the present study. Earlier studies found a strong relation between successful outcomes of problem drinkers and the degree to which their counselors displayed the skill of accurate empathy.<sup>[46, 47]</sup> Empathy is therefore seen as the basis of successful treatment with motivational interviewing.<sup>[48]</sup> As nurses can be expected to be empathetic, their empathy may therefore contribute to the lifestyle behavior change of the patients in both groups in this study.

Motivational interviewing focuses on increasing self-management by building self-efficacy. In a previous study, we found that self-efficacy for health-related behavior change was high in patients after TIA and ischemic stroke and was the strongest determinant of intention to quit smoking, increase physical activity and/or improve healthy diet.<sup>[33]</sup> However, in the present study self-efficacy was not significantly increased in the intervention group (aBeta 0.16, 95% CI -0.09-0.42), although it seemed to play a role in smoking cessation (Table 4 and 5). At present, it is not clear whether stroke patients are capable of adopting self-management. Possible cognitive problems, physical constraints and fear can affect this process. In this study, we did not assess cognition, but earlier studies showed that cognitive disorders are highly prevalent after stroke.<sup>[49, 50]</sup>

Strengths of our study are the detailed description of the content of the intervention and that the nurse was well trained in motivational interviewing and was coached and evaluated by an experienced trainer during the entire study. Furthermore, we used a relevant control group as both groups were seen by a nurse specialist, one with and one without specific motivational interviewing training and coaching. Our study has some limitations. First, the duration of the intervention (three months) might have been too short. Most patients are still rehabilitating during this phase and adapting to their disabilities. Hence, lifestyle behavioral change may not be their highest priority. Furthermore, the patients experienced fear, depressive symptoms and cognitive complaints that may have complicated the counselling. These problems were expressed during the counselling sessions and had more priority for the patients than lifestyle changes, but we did not measure cognition or depression in this study. Another limitation comes with the method of inclusion and data collection. After inclusion, patients were randomized and baseline data was collected. Patients were given time to complete the questionnaire during their stay. Unfortunately, some patients withdrew immediately after inclusion, or were discharged before the questionnaires were completed. In addition, patients sometimes appeared to have too much comorbidity or the first diagnosis was incorrect. This has

reduced the sample size. We also experienced a high percentage of lost to follow up (32%). Drop out was evenly distributed over both groups. However there were significant fewer patients with a TIA in the drop out group, and significant more smokers and patients who used more alcohol than recommended (data in supplemental file). This selective missing may be clinically relevant for the feasibility of using motivational interviewing, however given the width of the confidence intervals at six months follow up (Table 2) it is unlikely that final conclusions thereby would be affected. High drop out and distractions in conversations affected the feasibility of using motivational interviewing in this group. The extra visit to the hospital may be a too high threshold to take for patients. Because a relatively large number of smokers and alcohol users dropped out, having conversations at home or in primary settings can possibly increase the feasibility of the intervention.

In summary, the strong support in the control group, the timing and duration of the intervention, and cognitive problems may partially explain the lack of effect of motivational interviewing in our study. Therefore the role of motivational interviewing in supporting lifestyle behavior after TIA or ischemic stroke might be still possible and a key role for nurses in lifestyle behavior change in these patients could be considered.

At present, there is no strong evidence of the effectiveness of motivational interviewing on behavior change after a TIA or ischemic stroke. However, overall lifestyle behavior change was high in both groups and may be explained by the key role of specialized nurses in this study. Future studies should therefore focus on the role of nurses in behavioral change processes after stroke or TIA .

## **Conclusion**

Our results do not support the effectiveness of motivational interviewing in supporting lifestyle behavior change after TIA or minor ischemic stroke. However, the overall lifestyle behavior change was high and might be explained by the key role of specialized nurses in both groups.

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# General discussion





## GENERAL DISCUSSION

In my thesis, I have focused on different aspects of health-related behavior change after TIA or ischemic stroke. Before the start of my PhD project, my work at the outpatient clinic strongly motivated me to optimally support patients in changing health-related behavior after TIA or ischemic stroke. It was unknown which interventions are effective, how an intervention should be designed, to which patients it should be applied and at what time the intervention should be started. It was also unclear how these patients assess their own health-related behavior, which factors in their view facilitate or hamper health-related behavior change, and which support they request for changing health-related behavior. In this chapter, I will discuss the main findings of my studies, some methodological issues and implications for daily practice and future research.

### **Determinants of behavior change after TIA or ischemic stroke**

The first step towards developing a successful intervention is to identify factors that play a role in the behavior change process after TIA or ischemic stroke. This provides insight into the mechanism of behavioral change in this patient group and thereby direction on components that the intervention should contain. Therefore, the first part of my research focused on determinants of health-related behavior change after TIA or stroke. To gain insight in the process of health-related behavior change, we assessed determinants of intention to change health-related behavior and actual change based on the Protection Motivation Theory. We showed that self-efficacy, response-efficacy, and fear were independently associated with intention to change health-related behavior, with self-efficacy as the strongest determinant. In this quantitative study, we were unable to examine patients' subjective perspective of health behavior. Therefore, we also performed a qualitative study with in-depth, semi-structured interviews of patients' personal experience and view on health behavior change after TIA or ischemic stroke. In this study self-efficacy also appeared to be the most important determinant of behavior change. Patients mentioned self-efficacy both as barrier and facilitator. This finding that *self-efficacy* seems to play the most important role in health-related behavior change after TIA or ischemic stroke is in line with previous studies with other cardiovascular patients and in general populations<sup>[1-4]</sup>. Our finding that elderly patients, and those with a vascular history, depressive symptoms, higher BMI, less physical activity and increased fear had lower levels of self-efficacy for health-related behavior change suggests that self-efficacy is influenced by several factors. In contrast with earlier studies with patients with vascular disease (coronary heart disease, cerebrovascular disease or peripheral artery disease), we did not find associations between diabetes and smoking and lower levels of self-efficacy.

<sup>[5, 6]</sup> The variety of factors that influence each other makes the behavior change process

complicated, but also provides opportunities for influencing self-efficacy. Self-management approaches may help to increase self-efficacy for health-related behavior change after TIA or ischemic stroke. However, at present there is a lack of large studies on this subject. Self-efficacy is clearly not the only determinant of health-related behavior change after TIA or ischemic stroke. As the PMT states, coping is needed when a threat is experienced. We therefore added the determinant *fear* (threat) to the model because we expected it to play a role in health-related behavior change after TIA or ischemic stroke. Fear is often spontaneously reported by patients during regular follow up visit at the outpatient clinic. A meta-analysis of fear studied in different populations and different behaviors showed a significant interaction between threat (fear) and efficacy.<sup>[7]</sup> In these studies threat only had a motivating effect when high efficacy is present while fear was independently associated with intention to change in our study. Possibly, fear can be counterproductive and can lead to avoidance or denial-based forms of coping which explains the association with low self-efficacy. *Response efficacy* played a role in health-related behavior change as well. It seems to be a plausible determinant as behavior change is hard to accomplish and patients are only willing to change when they believe that this helps to reduce the risk of new vascular events. In my opinion, response efficacy could be influenced by increasing *knowledge* about the risk of recurrence and unhealthy behavior. We showed that stroke patients understand what constitutes healthy behavior but seem unable to adequately appraise their own health-related behavior. This finding is in my view very important for daily practice. When patients lack knowledge of risk factors for behavior change strategies one cannot expect them to adequately evaluate their own health-related behavior and to be highly motivated to change. Another possible reason for this inadequate judgement of health-related behavior can be denial. When patients experience anxiety, minimizing the unhealthy behavior and denying the effects of this behavior can be a way to reduce anxiety. As self-efficacy is developed by social persuasion,<sup>[8, 9]</sup> I expected *social support* to play a role in building self-efficacy for behavior change after TIA or ischemic stroke as well. However, we found no relation between social support and self-efficacy in the quantitative study. In contrast, in our qualitative study, besides knowledge, social support was indicated as most needed to change behavior. Possibly social support influences self-management in a different way than by improving self-efficacy. It seems plausible that social support influences the motivation to change as it is very hard to accomplish behavior change on your own. In line with this finding social support and knowledge has been found as important factors for changing health-related behavior after stroke in many other studies.<sup>[10-17]</sup>

All determinants have their own influence on behavior change, but also influence each other, which makes the behavior change process more complex. A previous review of stroke survivors' and family members' perspectives of lifestyle interventions also found a reciprocal and interrelated nature of social support, knowledge, self-confidence and motivation.<sup>[18]</sup> Factors can influence behavior change both directly and indirectly. For example, self-efficacy is influenced by fear, and response efficacy can be influenced by knowledge. Some of our results were in line with other studies, like the important role of self-efficacy in behavior change, which had not been studied in patients with TIA or ischemic stroke before. On the other hand, we did not find that stroke severity is a determinant of intention to health-related behavior change, contrary to my expectation that patients who experience disabilities after their stroke in everyday life would be more motivated to change. Although the severity of the ischemic stroke or TIA did not affect the intention to change, some potentially more vulnerable patients were found to have lower self-efficacy.

Up to 70% of patients have cognitive impairment after stroke. We expected cognition to influence the behavior change process, as cognition can influence mood, fatigue, activities, strain and eventually life satisfaction of patients after stroke and TIA.<sup>[19]</sup> These cognitive impairments together with the physical disabilities after stroke may hamper health-related behavior change in contrast to patient with other vascular diseases. Surprisingly, in our quantitative study cognition did not influence intention to change. Knowledge on the other hand was identified by patients as the most important factor for behavior change in our qualitative study. I did not expect knowledge to play a prominent role in changing health-related behavior after TIA or ischemic stroke as earlier studies showed that knowledge does not immediately lead to actual change.<sup>[20]</sup> Possibly, cognition does not directly influence intention, but rather the ability to absorb knowledge of disease, risk factors and a healthy behavior and self-reflection. Stroke and TIA patients therefore did not differ from other vascular patients in that respect. However, in the qualitative study patients did mention physical impairments such as fatigue and pain as barriers for behavior change. Patients also experienced stress and mood problems and environmental barriers including bad weather or mobility problems. These symptoms can also be experienced by patients with other vascular conditions, but the very nature of the neurological impairments, such as muscle weakness, aphasia or coordination disorders, is essentially different. Therefore, I still think that patients after stroke or TIA cannot be supported in health-related behavior change in the same way as other patients with other vascular disorders and deserve a tailored approach that provides due attention to their neurological disabilities.

At present the behavior change process after TIA or ischemic stroke is not completely clear. I showed that even when patients had the intention to change and had a high self-efficacy score and fear was present, there was often no actual change. This might be explained by our finding that more than half of the patients were satisfied with their health-related behavior and felt no urgency to change. Previous studies have shown a gap between intention and actual change in health-related behavior as well. <sup>[21]</sup>

### **Timing of an intervention to support patients in behavior change**

After assessing the main determinants of health-related behavior change after TIA or ischemic stroke, we focused on the optimal timing of an intervention to support patients in behavior change. We assessed this by studying change of determinants of health-related behavior intention to change over time. Self-efficacy and response-efficacy did not change over time and remained high. However, fear significantly decreased over time. Persistent high self-efficacy over time suggests that patients do not lose their confidence in behavior change when the stroke or TIA occurred longer ago. In a previous systematic review and meta-analysis of interventions focusing on modifiable behavior factors no difference was found between trials starting before or beyond three months after TIA or ischemic stroke. <sup>[22]</sup> However, since fear does decrease over months there seems to be a window of opportunity to support patients soon after their stroke. Therefore, in my view, an intervention to support patients in changing health-related behavior should start as soon as possible after the TIA or ischemic stroke.

### **Interventions to change health-related behavior after TIA or ischemic stroke**

We developed an intervention that we subsequently studied in a randomized clinical trial. I was trained in motivational interviewing and experienced positive effects of this approach during my consultations at the outpatient clinic. Motivational interviewing has been proven effective in adopting health-related behavior in patients with chronic diseases as well as in patients with cardiovascular diseases, in particular in supporting weight loss and reducing alcohol and tobacco intake. <sup>[23-25]</sup> These effects occur when conversations were short and repeated and may persist at least one year after counseling. <sup>[26]</sup> Therefore, patients in the intervention group received three consults of fifteen minutes at approximately four weeks, eight weeks and three months after inclusion. In our randomized controlled clinical trial motivational interviewing was not more effective in supporting health-related behavior change after TIA or minor ischemic stroke than conventional support. Although no overall effect of motivational interviewing on health-related behavior change could be found, 50% of the patients in the intervention group stopped smoking after three months compared with 33% in the control group suggesting an effect on smoking behavior. This



trend was no longer present after six months. Initially these results surprised me. The strong support in our control group, the timing and duration of the intervention, and cognitive problems may partially explain the lack of effect of motivational interviewing. An earlier meta-analysis of studies comparing motivational interviewing with a weak control group showed significantly higher effect sizes.<sup>[27]</sup> On the other hand, a high percentage of patients changed their health-related behavior (more than in our earlier study) in both groups. In my opinion, this is due to the nursing care that the patients received. Empathy, open questions, reflective listening and emphasis on patients' autonomy are the basic communication skills of motivational interviewing.<sup>[28]</sup> These skills can be particularly expected of nurses and may therefore have contributed to the health-related behavior change of the patients in both groups in our study. A recent systematic review and meta-analysis showed a significant effect on reducing blood pressure, improving physical activity, diet, medication adherence and knowledge of risk factors on secondary prevention interventions after TIA or ischemic stroke in which nurses had a primary role.<sup>[29]</sup> Nurses should therefore play an important role in supporting patients in behavior change after TIA or ischemic stroke. They are also trained in supporting self-management and can approach problems such as anxiety from both a medical and psychological point of view. Nurses are able to integrate education, self-management support, motivational interviewing and treatment of risk factors in outpatient consults or daily care to support patients in health-related behavior change after TIA or ischemic stroke.

## **Methodological considerations**

To the best of our knowledge, our prospective cohort study was the first to focus on determinants of health-related behavior change in patients with TIA or ischemic stroke. It provided insight in the behavior change process and potential point of applications for interventions. A limitation was that our study was not designed to change health-related behavior, and as a result only a few patients changed their health-related behavior. Therefore, we were not able to assess determinants of actual health-related change. This might partly explain why we only found a trend towards increased health-related behavior in patients with higher intention to change. Previous studies in health-related behavior has shown this intention-behavior gap as well<sup>[21]</sup>. The use of questionnaires in this prospective cohort study enabled us to collect a lot of information in a short time. We also thoroughly assessed the patients by conducting cognitive assessments and screening for depression. A limitation was that we were unable to examine patients' subjective perspective of health behavior. Therefore, we decided to examine the patients' personal experience and view on health-related behavior change after TIA or ischemic stroke in a subsequent qualitative study. Patients were able to talk freely, and factors and determinants emerged that were still unclear in our previous study. A limitation is that we did not collect any data other

than the information from the patients themselves. Therefore, we were unable to verify the patients' claims about their health-related behavior. Furthermore, motivational interviewing seemed so promising that we started our RCT before the results of the first study were fully known. As a result, we did not specifically focus on determinants of health-related behavior change after TIA or ischemic stroke in the intervention group. On the other hand, this study provided ample useful information, such as the importance of involvement of nurses in supporting health-related behavior change after TIA or ischemic stroke. In our prospective cohort study and randomized clinical trial, I experienced a high percentage of drop outs (32%). This high drop out rate of patients in secondary prevention programs after TIA or ischemic stroke has also been found in other studies with similar patients.<sup>[30]</sup> In my qualitative study, the majority of patients felt no need for *support* or already received support in changing health-related behavior. This possibly explains the high percentage of patients that did not complete the program.

### **Implications for daily practice**

In daily practice, one could start by paying more attention to the determinants of health-related behavior change after TIA or ischemic stroke. Screening of patients with unhealthy behavior for depression and anxiety to prevent these two factors from negatively influencing the behavior change process can be a first step. Furthermore, patients with depression or anxiety may need more attention in programs supporting health-related behavior changes as these factors should be treated before or during the behavior change process. Fear of a recurrent stroke may be used as an opportunity to motivate patients to change their health-related behavior. It can be discussed during consultation at the outpatient clinic and be related to health-related behavior change. Response efficacy could possibly be affected by increasing knowledge. As patients mentioned knowledge as an important requirement for behavior change they need proper information about risk factors and those with a low motivation deserve more attention and education. Relatives should be involved in interventions to change health-related behavior after TIA or ischemic stroke, by giving them the same information as the patients and making them aware of the importance of social support in the behavior change process. At present, I would not recommend active measurement of the determinants of health-related behavior change in daily practice. In my opinion there is not yet enough evidence for interventions improving self-efficacy or response efficacy for health-related behavior change after TIA or stroke.

### **Future research**

Future research should focus on interventions modifying the determinants of health-related behavior change after TIA or ischemic stroke. As patients identified knowledge, guidelines and social support as most needed factors to change and to preserve healthy

behavior future interventions should consist of education on health-related behavior, guidelines and strategies for change in order to influence response-efficacy and intention to change. Interventions should also focus on patients and their relatives and make use of patient group contacts to increase social support. Self-management approaches to increase patients' self-efficacy should also be a part of these interventions. Nurses should play a key role in the intervention. Special attention should be given to anxious patients, depressed patients, elderly patients and patients with a vascular history. Interventions to support patients after TIA or ischemic stroke should focus more on factors on which patients indicate the need of guidance and should provide support in every stage of change which could be supported by e-health solutions. These interventions should start as soon as possible after the ischemic stroke or TIA and, to prevent patients missing appointments, continue during the rehabilitation process or at home. It should take place in an accessible setting, preferably close to the patient's home. Such an integrated program in which the hospital, rehabilitation institutions and general practitioner work together should be developed and tested.

## **Conclusion**

The behavior change process after ischemic stroke or TIA is complex. We showed that stroke patients felt no urgency to change and experienced barriers for health-related behavior change such as fatigue, pain, mood and mobility problems which distinguishes them from other vascular patients. Nevertheless, we were able to identify factors that could help in developing an intervention. We demonstrated that self-efficacy, fear and response efficacy play a role in intention to change. Patients identified knowledge and social support as important factors for behavior change, which provides opportunities in supporting patients in health-related behavior change. Our RCT showed that as yet there is insufficient evidence to advocate the use of motivational interviewing, but the value of this technique needs further study. We also showed that the best time to start interventions is probably as soon as possible after the TIA or stroke. In these interventions nurses should play a key role. Our findings may help to develop and test targeted and efficacious interventions to support patients in health-related behavior change in order to reduce the recurrence risk and improve quality of life of after a TIA or ischemic stroke.

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# Summary

# Samenvatting







## SUMMARY

Stroke is the third cause of death and the leading cause of disability in developed countries. The incidence of stroke rises with increasing age and is expected to further increase the next years. After a TIA or ischemic stroke patients have an increased risk of recurrent stroke and other cardiovascular events. Supporting patients in changing health-related behavior after TIA or stroke may be an effective way to reduce stroke recurrence and is recommended in many guidelines. However, the majority of people with cardiovascular disease fail to sustain lifestyle modification in the long-term. At present, only limited and inconsistent data are available on interventions to support patients in health-related behavior change after TIA or ischemic stroke. Follow-up rates are short and patients often have physical barriers such as fatigue or pain, lack of knowledge, absent or inadequate social support, and cognitive problems which may also affect health-related behavior.

This thesis focuses on health-related behavior change after TIA or minor ischemic stroke. In the **Introduction**, I describe the background and rationale for the research in this thesis. The thesis consists of two parts. The first part focuses on determinants of health-related behavior change after TIA or ischemic stroke. In **Chapter 1.1**, I studied determinants of intention to change health-related behavior and actual change. In this prospective study, we aimed to identify factors that play a role in the health-related behavior change process after TIA or ischemic stroke. This can be the first step towards developing a successful intervention. In total, 100 patients with TIA or minor ischemic stroke completed questionnaires on behavioral intention and socio-cognitive factors from the Protection Motivation Theory including perception of severity, susceptibility, fear, response-efficacy and self-efficacy. Questionnaires on physical activity, diet and smoking were completed at baseline and at 3 months. Self-efficacy, response efficacy and fear were independently associated with behavioral intention, with self-efficacy as the strongest determinant of intention to increase physical activity (aBeta 0.40; 95% CI 0.12–0.71), adapt a healthy diet (aBeta 0.49; 95% CI 0.23–0.75), and quit smoking (aBeta 0.51; 95% CI 0.13–0.88). We found a trend to increased health-related behavior change in patients with higher intention to change. These determinants of intention to change health-related behavior after TIA or ischemic stroke should be taken into account in the development of future interventions promoting health-related behavior change in these group of patients. In **Chapter 1.2**, I describe a qualitative study of the determinants of health-related behavior change after TIA or ischemic stroke. We aimed to explore patients' perspectives on health-related behavior change, support in this change and sustaining healthy behavior. Eighteen patients with recent TIA or ischemic stroke underwent in-depth, semi-structured interviews. Interviews addressed barriers, facilitators, knowledge and support of health-related behavior change

framed by the Protection Motivation Theory and Transtheoretical Model. This study showed that these patients understand what constitutes a healthy lifestyle, but seem unable to adequately appraise their own health-related behavior. More than half of the patients were satisfied with their lifestyle and felt no urgency to change. In this study, self-efficacy was the most important determinant for health-related behavior change. It was reported by patients both as barrier and facilitator. Most of the patients stated that they did not need support or already received support in changing health behavior. Patients indicated knowledge, guidelines and social support as most needed to facilitate behavior change and to preserve a healthy lifestyle. This study suggests that increasing knowledge on lifestyle risk factors for ischemic stroke and improving self-efficacy may be important targets for lifestyle interventions after ischemic stroke. As self-efficacy appeared to play an important role we aimed to describe levels of self-efficacy of health-related behavior change and identify correlates of self-efficacy in patients with ischemic stroke or TIA. This study is described in **Chapter 1.3**. In this study, 92 patients with TIA or ischemic stroke completed questionnaires on self-efficacy for health-related behavior change and fear, social support and depressive symptoms. Patients reported high self-efficacy scores for health-related behavior change. Age, vascular history, more depressive symptoms, higher BMI, less physical activity, and fear were correlates of low self-efficacy levels. These patients deserve extra attention in interventions supporting behavior change after TIA or ischemic stroke. Additionally, we studied the optimal timing of an intervention to support health-related behavior change after TIA or ischemic stroke by studying the determinants of intention to change over time in **Chapter 1.4**. We studied differences between these determinants at baseline, six weeks and three months after TIA or ischemic stroke. Fear was significantly higher at baseline than at three months and started to decrease after six weeks. No change in self-efficacy or response efficacy was found. Since fear significantly decreased over time after TIA or ischemic stroke and self-efficacy and response efficacy scores remained high, the optimal timing to start an intervention to support patients in health-related behavior change after TIA or ischemic stroke seems directly after the stroke or TIA. The second part of this thesis focuses on supporting patients in health-related behavior change after TIA or minor ischemic stroke. **Chapter 2.1** describes a review on health education in patients with recent stroke or TIA. It shows that patients' basic knowledge of their disease and associated risk factors is not sufficient. Knowledge appeared to be a necessary factor for inducing change, but the process of modification of risk factors is a multistaged and complex one, requiring the right attitude, motivation and capacity to change behavior. We suggest that health education on stroke should start during the acute phase, and should be continued after discharge, and preferably be provided by the same persons. No specific method of health education is superior, although the individual and repetitive, active methods seem more successful. The

information should be patient-centred, interactive, personalized, flexible and repetitive. It should create opportunities to apply the new knowledge that leads to attitude changes. Nurse practitioners could combine vascular care coordination with promoting self-management or other cognitive behavioral approaches to induce healthy lifestyle. They could also pay attention to patients' relatives, who play an important role in inducing and promoting healthy lifestyle behaviors in patients. This part ends with a randomized controlled open label phase II trial with blinded endpoint assessment in which we studied the effects of motivational interviewing to encourage health-related behavior change after TIA or ischemic stroke. We describe this study in **Chapter 2.2**. We included 136 patients (of whom 68 were assigned to the intervention group). The intervention consisted of three 15-minute visits in three months by a motivational interviewing trained nurse practitioner. Patients in the control group received standard consultation after one and three months by a nurse practitioner. Our results did not support the effectiveness of motivational interviewing in supporting health-related behavior change after TIA or minor ischemic stroke. The strong support in the control group, the timing and duration of the intervention, and cognitive problems may partially explain the lack of effect of motivational interviewing in this study. However, the overall health-related behavior change was high and might be explained by the key role of specialized nurses in both groups. In **Chapter 3**, I conclude that the behavior change process after ischemic stroke or TIA is complex. We showed that stroke patients felt no urgency to change and experienced barriers for health-related behavior change such as fatigue, pain, mood and mobility problems which distinguishes them from other vascular patients. Nevertheless, we were able to identify factors that could help in developing an intervention. We demonstrated that self-efficacy, fear and response efficacy play a role in intention to change. Patients identified knowledge and social support as important factors for behavior change, which provides opportunities in supporting patients in health-related behavior change. We also showed that the best time to start interventions is probably as soon as possible after the TIA or stroke. In these interventions nurses should play a key role. Our findings may help to develop and evaluate targeted and efficacious interventions to support patients in health-related behavior change in order to reduce the recurrence risk and improve quality of life of after a TIA or ischemic stroke. Future research should focus on interventions modifying the determinants of health-related behavior change after TIA or ischemic stroke. These interventions should consist of education for patient and relatives, self-management approaches and special attention should be given to anxious patients, depressed patients, elderly patients and patients with a vascular history.



## SAMENVATTING

Een beroerte (herseneninfarct of hersenbloeding) is de derde doodsoorzaak en de belangrijkste oorzaak van invaliditeit in de westerse wereld.. De incidentie van een beroerte stijgt met de leeftijd en zal naar verwachting de komende jaren verder toenemen. Na een TIA of herseneninfarct hebben patiënten vaker opnieuw een beroerte en andere cardiovasculaire aandoeningen. Het ondersteunen van patiënten bij het veranderen van gezondheid gerelateerd gedrag na een TIA of beroerte kan een effectieve manier zijn om het risico op een recidief beroerte te verlagen en wordt in nationale en internationale richtlijnen aanbevolen. Veel patiënten met hart-en vaatziekten hebben moeite om een gezonde leefstijl vol te houden. De wetenschappelijk basis over gezonde leefstijl bevorderende interventies na een TIA of herseneninfarct is beperkt. De studies die zijn verricht zijn klein of follow-up is kort. Daarnaast ervaren patiënten vaak fysieke barrières, zoals vermoeidheid of pijn, gebrek aan kennis, afwezige of onvoldoende sociale steun en cognitieve problemen die ook het gezondheidsgerelateerd gedrag kunnen beïnvloeden.

Dit proefschrift richt zich op gezondheidsgerelateerde gedragsverandering na een TIA of een klein herseneninfarct. In de **introdunctie** beschrijf ik de achtergrond en de aanleiding voor het onderzoek in dit proefschrift. Het proefschrift bestaat uit twee delen. Het eerste deel richt zich op determinanten van gezondheidsgerelateerde gedragsverandering na een TIA of herseneninfarct. In **hoofdstuk 1.1** bestudeerde ik determinanten van intentie om gezondheidsgerelateerd gedrag te veranderen en daadwerkelijke verandering. In dit prospectieve onderzoek wilden we factoren identificeren die een rol spelen in het gezondheidsgerelateerde gedragsveranderingsproces na een TIA of herseneninfarct. Dit kan de eerste stap zijn om een succesvolle interventie om leefstijlverandering te ondersteunen te ontwikkelen. In totaal hebben 100 patiënten na een TIA of herseneninfarct vragenlijsten ingevuld over gedragsintentie en sociaal-cognitieve factoren uit de Protection Motivation Theory, waaronder beleving van ernst, gevoeligheid, angst, respons-effectiviteit (de overtuiging dat verandering effect heeft) en zelfeffectiviteit (het vertrouwen in eigen kunnen). Vragenlijsten over lichamelijke activiteit, dieet en roken werden ingevuld bij begin van het onderzoek en na drie maanden. Zelfeffectiviteit, response effectiviteit en angst bleken onafhankelijk geassocieerd met gedragsintentie, met zelfeffectiviteit als de sterkste determinant van intentie om lichamelijke activiteit te verhogen (aBeta 0,40; 95% BI 0,12-0,71), een gezonder voedingspatroon aan te nemen (aBeta 0,49; 95 % BI 0,23-0,75) en te stoppen met roken (aBeta 0,51; 95% BI 0,13-0,88). We vonden een neiging naar verhoogde gezondheid gerelateerde gedragsverandering bij patiënten met een hogere intentie om te veranderen. Het is van belang om met deze determinanten van de intentie om gezondheidsgerelateerd gedrag na een TIA herseneninfarct te veranderen rekening te

houden bij de ontwikkeling van toekomstige interventies die gezondheidsgerelateerde gedragsverandering bij deze patientengroep bevorderen. In **hoofdstuk 1.2** beschrijf ik een kwalitatieve studie van de determinanten van gezondheidsgerelateerde gedragsverandering na een TIA of herseninfarct. We hadden als doel om de perspectieven van patiënten op gezondheidsgerelateerde gedragsverandering, ondersteuning bij deze verandering en volhouden van gezond gedrag te onderzoeken. Achttien patiënten met een recente TIA of herseninfarct ondergingen diepgaande, semi-gestructureerde interviews. Interviews gingen in op barrières, facilitators, kennis en ondersteuning van gezondheidsgerelateerde gedragsverandering, gebaseerd op de Protection Motivation Theory en Transtheoretic Model. Deze studie liet zien dat patiënten begrijpen wat een gezonde leefstijl is, maar niet in staat zijn om hun eigen gezondheidsgerelateerd gedrag adequaat te beoordelen. Meer dan de helft van de patiënten was tevreden met hun leefstijl en voelde geen urgentie om het te veranderen. In deze studie was zelfeffectiviteit de belangrijkste bepalende factor voor gezondheidsgerelateerde gedragsverandering. Het werd door patiënten gemeld als barrière en als facilitator. De meeste patiënten verklaarden dat ze geen ondersteuning nodig hadden of al ondersteuning kregen bij het veranderen van hun gezondheidsgedrag. Patiënten gaven aan dat kennis, richtlijnen en sociale steun het meest nodig zijn om gedragsverandering te vergemakkelijken en een gezonde leefstijl te behouden. Deze studie suggereert dat het vergroten van kennis over leefstijlfactoren voor herseninfarct en het verbeteren van zelfeffectiviteit belangrijke aangrijpingspunten kunnen zijn voor leefstijlinterventies na een herseninfarct. Gezien zelfeffectiviteit een belangrijke rol leek te spelen, streefden we ernaar de niveaus van zelfeffectiviteit van gezondheidsgerelateerde gedragsverandering te beschrijven en correlaten van zelfeffectiviteit te identificeren bij patiënten met een herseninfarct of na een TIA. Deze studie wordt beschreven in **hoofdstuk 1.3**. In deze studie vulden 92 patiënten met een TIA of herseninfarct vragenlijsten in over zelfeffectiviteit voor gezondheidsgerelateerde gedragsverandering en angst, sociale steun en depressieve symptomen. Patiënten rapporteerden hoge zelfeffectiviteit scores voor gezondheidsgerelateerde gedragsverandering. Leeftijd, een voorgeschiedenis met hart en vaatziekten, meer depressieve symptomen, hogere BMI, minder lichamelijke activiteit en angst waren correlaten van lage niveaus van zelfeffectiviteit. Deze patiënten verdienen extra aandacht bij interventies ter ondersteuning van gedragsverandering na een TIA of herseninfarct. Daarnaast hebben we de optimale timing van een interventie ter ondersteuning van gezondheidsgerelateerde gedragsverandering na TIA of herseninfarct bestudeerd door de verandering van determinanten van de intentie in de loop van de tijd te bestuderen in **hoofdstuk 1.4**. bestudeerden we verschillen tussen deze determinanten bij aanvang van de studie, zes weken en drie maanden na een TIA of herseninfarct. Angst was significant hoger bij aanvang dan na drie maanden en begon na zes weken af te nemen. Er werd geen

verandering in zelfeffectiviteit of response-effectiviteit gevonden. Aangezien angst na een TIA of herseninfarct na verloop van tijd aanzienlijk afnam en de scores voor zelfeffectiviteit en response-effectiviteit hoog bleven, lijkt het optimale moment om een interventie te starten om patiënten te ondersteunen bij gezondheidsgerelateerde gedragsverandering direct na de beroerte of TIA. Het tweede deel van dit proefschrift richt zich op het ondersteunen van patiënten bij gezondheidsgerelateerde gedragsverandering na TIA of klein herseninfarct. **Hoofdstuk 2.1** beschrijft een overzicht van gezondheidsvoorlichting bij patiënten met een recent herseninfarct of TIA. Het laat zien dat de basiskennis van patiënten over hun ziekte en bijbehorende risicofactoren niet voldoende is. Kennis leek een noodzakelijke factor te zijn om verandering teweeg te brengen, maar het proces van aanpassing van risicofactoren is een meertraps en complex proces, dat de juiste houding, motivatie en capaciteit vereist om gedrag te veranderen. Wij stellen voor dat voorlichting over een beroerte tijdens de acute fase moet beginnen en na ontslag moet worden voortgezet en bij voorkeur door dezelfde personen moet worden gegeven. Geen specifieke methode van gezondheidsvoorlichting is superieur, hoewel de individuele en herhaalde methoden succesvoller lijken. De informatie moet patiëntgericht, interactief, gepersonaliseerd en flexibel zijn. Het moet kansen creëren om de nieuwe kennis toe te passen die tot attitudeveranderingen leidt. Verpleegkundigen zouden vasculaire zorg kunnen combineren met het bevorderen van zelfmanagement of een andere cognitieve gedragsbenadering om een gezonde levensstijl te induceren. Ze kunnen ook aandacht besteden aan familieleden van patiënten, die een belangrijke rol spelen bij het stimuleren en bevorderen van gezond leefstijlgedrag bij patiënten. Dit deel eindigt met een gerandomiseerde gecontroleerde open-label fase II-onderzoek met een geblindeerde eindpuntbeoordeling, waarin we de effecten van motiverende interviews hebben onderzocht om gezondheidsgerelateerde gedragsverandering na TIA of herseninfarct aan te moedigen. We beschrijven dit onderzoek in **hoofdstuk 2.2**. We onderzochten 136 patiënten (waarvan 68 werden toegewezen aan de interventiegroep). De interventie van drie maanden bestond uit drie bezoeken van 15 minuten aan een verpleegkundig specialist die was opgeleid in motiverend interviewen. Patiënten in de controlegroep ontvingen een standaardconsult na één en drie maanden door een verpleegkundig specialist welke geen specifieke motiverende technieken toepaste. Onze resultaten ondersteunden de effectiviteit van motiverende interviews bij het ondersteunen van gezondheidsgerelateerde gedragsverandering na TIA of een herseninfarct niet. De sterke ondersteuning in de controlegroep, de timing en duur van de interventie en cognitieve problemen kunnen gedeeltelijk het gebrek aan effect van motiverende interviews in dit onderzoek verklaren. De algemene gezondheidsgerelateerde gedragsverandering was echter hoog en kan worden verklaard door de sleutelrol van verpleegkundig specialisten in beide groepen. In **hoofdstuk 3** concludeer ik dat het gedragsveranderingsproces na

een een herseninfarct of TIA complex is. We hebben aangetoond dat patiënten met een TIA of herseninfarct geen urgentie voelden om te veranderen en barrières ervaren voor gezondheidsgerelateerde gedragsverandering zoals vermoeidheid, pijn, stemming en fysieke problemen waarmee ze zich onderscheiden van andere vasculaire patiënten. Desondanks konden we factoren identificeren die kunnen helpen bij het ontwikkelen van een interventie. We hebben aangetoond dat zelfeffectiviteit, angst en response effectiviteit een rol spelen bij de intentie om te veranderen. Patiënten identificeerden kennis en sociale steun als belangrijke factoren voor gedragsverandering, wat kansen biedt bij het ondersteunen van patiënten bij gezondheidsgerelateerde gedragsverandering. We hebben ook aangetoond dat de beste tijd om met interventies te starten waarschijnlijk zo snel mogelijk na de TIA of beroerte is. Bij deze interventies moeten verpleegkundig specialisten een sleutelrol spelen. Onze bevindingen kunnen helpen bij het ontwikkelen en evalueren van gerichte en doeltreffende interventies om patiënten te ondersteunen bij gezondheidsgerelateerde gedragsverandering om het recidiefrisico te verminderen en de kwaliteit van leven na een TIA of herseninfarct te verbeteren. Toekomstig onderzoek moet gericht zijn op interventies die de determinanten van gezondheidsgerelateerde gedragsverandering na TIA of herseninfarct kunnen veranderen. Deze interventies moeten bestaan uit voorlichting voor patiënten en familieleden, zelfmanagementondersteuning en speciale aandacht moet worden besteed aan angstige patiënten, depressieve patiënten, oudere patiënten en patiënten met een vasculaire voorgeschiedenis.







**Dankwoord**

**Portfolio**

**About the author**





## DANKWOORD

Peter, jou wil ik als eerste bedanken. Vijftien jaar geleden vroeg je mij een nieuwe functie op de polikliniek te vervullen en sindsdien heb je mij altijd veel vertrouwen gegeven. Na enig aandringen ben ik met wetenschappelijk onderzoek begonnen en op dezelfde manier ben ik met mijn Master Advanced Nursing Practice gestart. Je hebt mij veel ruimte gegeven om mijzelf te ontwikkelen en het op mijn eigen tempo te doen. Bedankt voor je rust, vertrouwen en alle mogelijkheden die je mij gegeven hebt. Je hebt deuren voor mij geopend die voor de meeste verpleegkundigen gesloten zijn. Zonder jou had ik hier niet gestaan.

Beste Heleen, zonder jou was ik nooit aan dit traject begonnen. Ik vond het al fijn om met je samen te werken op de verpleegafdeling en zonder jouw ondersteuning wilde ik überhaupt niet aan dit avontuur beginnen. Door mij enerzijds de ruimte te geven en anderzijds te motiveren en zachtjes te pushen heb je mij heel goed begeleid. Je hebt ook veel geduld gehad in de tijden dat ik eigenlijk te druk was voor het onderzoek. Ik ben onder de indruk van je kennis en onderzoeksvaardigheden en trots dat ik je mijn copromotor mag noemen. Dat jij met je drukke baan en gezin nog tijd vindt om onderzoek te doen vind ik ontzettend knap. Ik hoop nog jaren met je samen te werken!

Diederik en Hester, jullie wil ik ook erg bedanken. Ik ben onder de indruk van jullie kennis, kunde en ontspannen houding. Dat jullie mee wilden denken en hebben meegewerkt aan mijn projecten vind ik dan ook een eer. Ik ben heel dankbaar dat ik van jullie expertise gebruik heb mogen maken en vind het bijzonder dat jullie zo laagdrempelig bereikbaar zijn. Lenneke, jou wil ik ook erg bedanken voor de kritische, maar opbouwende opmerkingen en de handvaten die je hebt geboden bij de start van het onderzoek.

Leden van de leescommissie, prof. dr. Bindels, prof. dr. van den Berg en prof. dr. van Dijk, bedankt het lezen van het manuscript en de opbouwende reacties. Dr. Taal wil ik graag bedanken voor de betrokkenheid bij het onderzoek en begeleiding bij mijn bezoek aan Twente. Prof. dr. Burdorf wil ik bedanken voor zijn deelname in de grote commissie. Dr. Sol, jaren geleden heb ik een voordracht van u bijgewoond over zelf-effectiviteit bij cardiovasculaire patiënten. Ik wist toen nog niets van theorieën of determinanten van gedragsverandering, maar vond het ontzettend interessant. Onbewust heeft u een belangrijke rol gespeeld in het onderzoek dat volgde. Hartelijk dank voor uw inspiratie.

Lieve Maaïke, voor jou is een bijzonder woord in dit boekje op zijn plaats. Wat werk je hard, wat heb je geworsteld, en wat fijn dat je nu een plek hebt gevonden waar je lekker werkt. Wij hebben veel meegemaakt; genoten van congressen, samen 'opgegroeid' op de poli, gelachen en elkaar gesteund. Superfijn dat jij vandaag naast me staat!

Ook wil ik alle verpleegkundig specialisten, physician assistants en verpleegkundig consulenten van de neurologie en neurochirurgie bedanken. Bedankt voor jullie luisterend oor en steun! Wat hebben we gezellige jaren gehad op Ba 493 en gelukkig vinden wij in de nieuwbouw ook nog tijd om met elkaar mee te leven.

Ook de leden van de neurovasculaire groep wil ik bedanken. Paula, Bob, Kamran en Fop: bedankt voor de samenwerking, steun en interesse de afgelopen jaren. En Inger, Susan, Ladbon, Anouk, Lisa en Dianne: het was fijn om met jullie te werken en op te trekken tijdens de congressen. Bedankt voor jullie betrokkenheid, hulp en tips.

Naziha, Alia en Esther, jullie wil ik ook bedanken voor jullie hulp op de 'oude' SPP. Wat een werk hebben we daar met elkaar verzet! Erg bedankt dat jullie wilde helpen met de dataverzameling.

Pauline, Annely, Alis en Jeroen: bedankt voor jullie hulp bij het includeren van patiënten en invoeren van de gegevens. Als junior onderzoeker was het voor mij leerzaam om op jullie vragen antwoorden geven, en ik vond het heel leuk om jullie te begeleiden.

Meiden van de HBO-V, inmiddels is het meer dan 20 jaar geleden dat we elkaar ontmoetten. Wat waren we jong en vol plannen. En wat zijn we allemaal goed terecht gekomen! Ik geniet van onze contacten en hoop dat we er nog 20 jaar aan vast kunnen plakken.

Mijn studiegenoten van de Master Advanced Nursing Practice (MANP) opleiding en in het bijzonder Anna en Laura, dank voor de support en gezellige uren tijdens en na de opleiding!

En dan mijn vriendinnen. Carla, bedankt voor je vriendschap. Heerlijk als je elkaar zo lang kent dat je aan een half woord genoeg kunt hebben en aan de andere kant uren kunt praten. Marlies, wat kennen we elkaar al lang en wat geniet ik van onze contacten. Vriendinnen en schoonzussen tegelijk: beter wordt het niet! En Jantine, wat fijn dat je altijd een luisterend oor biedt en we zo kunnen lachen. En heerlijk dat je vandaag naast me staat om mij te steunen. Daarnaast wil ik ook jullie 'husbands' bedanken. Karsten, Hans en Peter bedankt dat ik jullie geliefden regelmatig mag lenen!

Lieve familie Brouwer, 20 jaar geleden kwam ik in jullie familie. Soms wat overweldigend, maar ook reuze gezellig zo'n groot gezin! Bedankt voor jullie steun en interesse de afgelopen jaren.

Natuurlijk wil ik ook mijn familie bedanken. Marjolein, Petra en Jolanda; samen zijn we opgegroeid in een meidengezin met wat mij betreft een jongensmentaliteit: niet huilen maar opstaan en doorgaan. Ik ben trots op de stoere vrouwen die jullie daardoor geworden zijn. Bedankt voor jullie gezelligheid, steun en luisterende oor! Pappa en Mamma bedankt voor de mogelijkheden die jullie mij hebben gegeven en het doorzettingsvermogen dat jullie mij hebben geleerd.

En dan last but not least mijn fijne gezin. Renze, wat zijn we al lang bij elkaar en wat is er veel gebeurd. Elkaar jong ontmoet en een beetje samen volwassen geworden. We hebben ontdekt dat gewoon eigenlijk heel bijzonder is en genieten daar nu volop van. Superfijn dat ik alles met je kan delen en jij mijn veilige basis vormt. Bedankt voor je steun, bemoedigende én relativerende woorden tijdens dit promotietraject. You are the love of my life (this one and the next).

En dan nog een speciaal woord voor mijn jongens. Wat ben ik trots op jullie en wat is het mooi om jullie te zien opgroeien! Je kunt altijd verder leren en avonturen beleven als je maar durft. Dus Tom, Niels en Joost blijf denken aan Pippi:  
"ik heb het nog nooit gedaan, dus denk dat ik het wel kan!"





## PHD PORTFOLIO

	Year	ECTS
<b>Research skills</b>		
Methodology of research and preparation of grant applications	2009	1
Evidence based Care for nurses	2011	1
GCP registration course (BROK)	2013	1
<b>International presentations</b>		
ESC, London, poster presentation	2013	1
ESC, Nice, poster presentation	2014	1
ESC, Nice, oral presentation	2014	1
ESOC, Glasgow, poster presentation	2015	1
ESOC Barcelona, poster presentation	2016	1
ESOC, Prague, poster presentation	2017	1
<b>National presentations</b>		
Scientific meeting neurovascular group, Amsterdam	2013	1
Annual congress V&VN, Driebergen	2014	1
<b>Seminars and workshops</b>		
Motivational Interviewing training V&VN, Zevenhuizen	2011	1
Motivational Interviewing Expert training (6 days), Eindhoven	2013	2
Continuing coaching in Motivational interviewing, Eindhoven	2013-2016	2
European Stroke Organisation Conference, Gothenborg	2018	1
European Stroke Organisation Conference, Milan	2019	1
Rotterdam Stroke Service Conference	2018-2020	2
COEUR: patient central in research	2019	1
<b>Teaching activities</b>		
Supervising medical student Master thesis	2016	2
Supervising medical student Master thesis	2015	2
Supervising medical student Master thesis	2014	2
Lectures for geriatric, ER and stroke nurses at Erasmus MC and Albeda college	2009-present	2
<b>Other</b>		
President of group of stroke nurses Rijnmond	2007-present	1
Member of stakeholders committee of Benefit trial	2018-present	1
<b>Funding</b>		
Funding from Evidence Based care for Nurses fund (25.000), Erasmus MC, Rotterdam	2014	



## **ABOUT THE AUTHOR**

Dorien Brouwer-Goossensen was born on March 16<sup>th</sup>, 1982 in Leiderdorp, the Netherlands. When she was ten years old she moved to Capelle aan den IJssel where she finished her primary school. After finishing secondary school at Gereformeerde Scholengemeenschap Rotterdam she studied for Registered Nurse at Hogeschool Rotterdam in 2000. For four years she worked at the Daniel den Hoed Clinic, Sophia's Children Hospital and Erasmus University Medical Hospital in Rotterdam. She graduated as a registered nurse on the Neurology ward in 2004. In 2005 she started working as a nurse specialist for neurovascular patients at the outpatient clinic of the Erasmus University Medical Hospital. In 2010 she started the research underlying this thesis at the Department of Neurology under supervision of Prof. dr. P.J. Koudstaal and dr. H.M. den Hertog. In the years following she coordinated the DECIDE study (Determinants of health-related behavior change after TIA and ischemic stroke). She received funding for the MOTIVE study (€25.000 from the Evidence Based Care for Nurses fund), studying effects of motivational interviewing to support health-related behavior change after TIA or ischemic stroke. From 2013 until 2016 she followed several Motivational Interviewing basic courses and finished a Motivational Interviewing expert training. After fourteen years of experience as a nurse specialist she completed her Master of Advanced Nursing Practice in 2018. She currently lives in Nieuwerkerk aan den IJssel with her husband Renze Brouwer and three children; Tom (2006), Niels (2008) and Joost (2010).





