

Tailoring Self-Management in Chronic Care

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Tailoring Self-Management in Chronic Care

Zelfmanagement op maat voor patiënten met een chronische ziekte

(met een samenvatting in het Nederlands)

Proefschrift

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1

Introduction & outline

Self-management is booming. Governmental policies aim at increasing self-management initiatives and worldwide researchers are studying how to enhance effectiveness of self-management support. Current health policy is encouraging an active role of patients and active collaboration between patient and care givers and thereby increasing efficiency and quality of health care¹. These changes in health care, where a more active role is required of patients, are in line with the recent defined concept of health as suggested by Huber and colleagues who state that “health is the ability to adapt and to self-manage, in the face of social, physical and emotional challenges”². However, the implementation of self-management in clinical practice presently faces serious challenges. The following quote from a primary care nurse working in chronic care illustrates this:

Every consultation I start by asking the patient “are there any topics you want to discuss today?” And well.. often that’s not the case. Then I think by myself, well.. I can keep fishing.. and say something like.. “well, there has to be something you want to talk about, isn’t it?” well yeah, often that’s just not the case and I do my measurements and off they go, see you in 3 months. I can make all sorts of plans but it comes down to making day by day decisions what you can and can’t do and how to do it, and well, that means customizing and makes it hard to do things in a standard manner.. People are so diverse, but that’s also the fun of it.

In this chapter we will explain why self-management is important in people with a chronic condition, what self-management entails, explain the concept of tailoring self-management support and why we think this can contribute to more effective self-management. Finally, the aims and the outline of this thesis are presented.

Chronic diseases - as the domain of self-management

In the Netherlands there are around 5.3 million people living with one or more chronic diseases³. Almost 80% of the people older than 75 years of age have at least one chronic disease. These numbers are comparable to other European countries³. Examples of prevalent chronic diseases are cardiovascular diseases (e.g. cardiovascular events, heart failure), respiratory diseases (e.g. chronic obstructed pulmonary disease) and diabetes. Chronic disease prevalence has increased in the last years and will increase even further due to ageing and disease inducing lifestyle at one hand, and early recognition of (risk of) diseases and better treatment on the other hand^{3,4}. Chronic diseases last long but generally progress slowly; they can usually not be cured, but progression and deterioration can often be prevented through medication, therapy and/or lifestyle modification⁵. People with a chronic disease often make doctor visits, use (many) medication(s) and often need extra care such as physiotherapy, home care, and medical devices.

The increasing prevalence of chronic diseases, the need for surveillance to prevent complications, and the need for managed care changed medical care over the past

years. A major change is the development of disease management programs based on evidence based care standards for systematic monitoring. Another important change is that for cost-effectiveness reasons chronic disease management is being transferred from secondary to primary care and recently from the primary care physician to the practice nurse⁶. Furthermore, health care has shifted from paternalistic models that place the patient as passive recipient of care towards models in which active involvement of patients is demanded⁷. This is expressed in the chronic care model that states that with proper training and support, people can change the progression of disease by becoming active agents in their own health⁸. Recently, the concept of self-management was increasingly incorporated in chronic disease management to strengthen the role of the patient and to reduce health care costs.

Definition of self-management

Self-management refers to “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life”⁷. Self-management consists of three core tasks, namely medical management, role management and emotional management and six skills—problem solving, decision making, resource utilization, the formation of a patient–provider partnership, action planning, and self-tailoring⁹, as described by Lorig and Holman. Medical management often includes lifestyle changes to decrease further progression of the disease, such as smoking cessation in chronic obstructive pulmonary disease, diet adjustment and increasing physical activity in cardiovascular disease and obesity. To improve the prognosis of diabetes patients need to become more physically active, lose weight, quit smoking, and minimize their alcohol consumption. Furthermore, people often need to take medication and need to know when to consult their doctor. Since patients need to learn to live with their chronic condition in their daily lives this may also ask for rearrangements in their way of life, and the creation of new meaningful roles. Patients may also have to deal with the emotional consequences of living with a chronic disease. All these aspects of chronic disease management require adequate self-management.

Self-management is a relatively new concept and over the last 10-20 years many self-management interventions were developed to increase self-management capacity in patients. Some self-management interventions are disease specific (e.g. the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) program for people with type 2 diabetes¹⁰, of which the Dutch version is called PRISMA¹¹), while others more generically target a population of patients with a chronic disease (e.g. the Chronic Disease Self-Management Program - CDSMP¹²). Furthermore, self-management support interventions may vary from the provision of disease specific information to

extensive self-management programmes targeting all aspects of self-management. Jonkman and colleagues defined self-management interventions as follows: “Self-management interventions aim to equip patients with skills to actively participate and take responsibility in the management of their chronic condition in order to function optimally through at least knowledge acquisition and a combination of at least two of the following: stimulation of sign/symptom monitoring, medication management, enhancing problem-solving and decision-making skills for medical treatment management, and changing their physical activity, dietary and/or smoking behaviour.”¹³ However, many other definitions of self-management exist and interventions are very heterogeneous with regards to content, mode and dose of delivery.

Effectiveness of self-management

Systematic reviews have reported positive results of many self-management interventions on one or more outcome measures. Research shows that self-management interventions have positive effects on hospital (re-)admissions¹⁴⁻¹⁶, quality of life¹⁶, blood glucose levels, systolic blood pressure, body weight, medication need and knowledge in diabetics¹⁷. A systematic review on interventions in patients with different chronic diseases concluded that self-management education programs resulted in small to moderate effects for selected chronic diseases¹⁸. However, we have to conclude that despite these promising outcomes, effect sizes are small.

The difficulty of performing systematic reviews and meta-analyses is that the content of interventions can vary, as do target populations, professionals delivering the intervention (physicians, nurses or lay leaders), and outcome measures. This hampers drawing valid and uniform conclusions.

Therefore, the conclusion is that self-management interventions show some promising results, that we expect self-management to be of growing importance but that at present the evidence regarding what is effective and in whom is still inadequate and heterogeneous. More knowledge is needed on what causes self-management support to be successful and in which patients.

Tailoring self-management

Since interventions are not effective in everyone, tailoring self-management to the specific needs of an individual is expected to improve self-management efficacy¹⁹. Tailoring was defined by Kreuter et al²⁰. as: “Any combination of information or change strategies *intended to reach one specific person*, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment.” Thus tailoring refers to a process of creating individualized intervention materials or strategies, which aim to enhance the relevance of the information presented to the individual, and thereby producing greater desired changes in response to communications¹⁹. Individualized strategies can entail variations in content of self-management aspects, mode of delivery

and dose of delivery (e.g. frequency of consultations, duration).

To be able to tailor chronic care to the individual it is important to know what patient factors determine self-management capacity and which patients (with what factors) will respond to self-management support²¹.

Self-management support

Since the evidence shows a positive effect of self-management support, it is now widely recommended in clinical care guidelines. In the Netherlands, self-management support is most often provided by the primary care nurse or a specialized nurse in secondary care, and physicians mainly play a supportive role.

Definitions of self-management support vary. Johnston and colleagues wrote “self-management centres on the individual, and their family supports, by using collaborative goal setting and a variety of self-efficacy strategies that can include effective problem-solving, monitoring their own condition, relapse prevention plans, patient education, group supports and shared decision making”²². Self-management support demands a shift in the role of healthcare professionals from merely delivering information and focussing on clinical outcomes to coaching patients in making day-to-day decisions leading to improved self-management and better outcomes²³. Since health care is changing toward patient-centred care, defined as the provision of care that is respectful and responsive to patient preferences, needs, and values, self-management support should be offered to the individual in a tailored manor. Besides preferences, needs and values, more knowledge is needed on what factors influence self-management capacity, in order to determine which support is necessary in an individual patient. In addition, knowledge is needed on how self-management support is delivered in chronic care and what patient factors are taken into account by care providers in tailoring self-management.

Despite the integration in clinical guidelines, self-management support is not (yet) an integral part of clinical practice²⁴. There is a gap between the potential benefit of self-management and the reality of chronic care delivery at present. There are several issues that determine this gap:

- Adherence to guidelines - Self-management has been implemented in clinical care guidelines but we do not know how this has landed in clinical practice.
- The perceptions of care providers on (tailoring) self-management.
- The capacities of care providers to adequately apply self-management support.
- The capacities of patients with regard to self-management.
- The fit between patients’ capacities and how care is tailored to the individual patient by the care provider.

Aims and outline of the present thesis

The aim of this thesis is to explore how self-management support is perceived and performed in clinical practice. Furthermore, we aim to explore how self-management support can become more effective by studying various aspects of tailoring. The focus will be on exploring what perceptions care providers have towards tailoring self-management, how self-management is tailored in clinical practice, what patient factors are involved in tailoring self-management support, and what nurses need to provide tailored self-management support. In the different chapters we study the concept of tailoring self-management support in patients with different chronic conditions.

- In the first part, we will explore which patient factors are associated with activation for self-management (Ch. 2) and identify determinants of change following self-management support (Ch. 3). Furthermore, we explore how tailoring is applied in self-management interventions for patients with heart failure (Ch. 3).
- In the second part, we will qualitatively explore how nurses perceive self-management and how they individualize self-management support (Ch. 4). In chapter 5 we will quantitatively explore health care providers' perceptions regarding self-management support, the type of self-management support that is applied in practice and what patient factors determine its success. In chapter 6 we will determine which patient factors influence the decision-making of primary care professionals in providing self-management support.
- In the last part (Ch. 7), we will further explore patient factors that need to be addressed during individualized self-management support and the competences and training that nurses need to be able to perform self-management support.
- Finally, we will reflect on the results of these studies and synthesize the conclusions in the general discussion (Ch. 8).

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2

Patient and disease characteristics associated with activation for self-management in patients with diabetes, chronic obstructive pulmonary disease, chronic heart failure and chronic renal disease: a cross-sectional survey study

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Abstract

Background A substantial proportion of chronic disease patients do not respond to self-management interventions, which suggests that one size interventions do not fit all, demanding more tailored interventions. To compose more individualized strategies, we aim to increase our understanding of characteristics associated with patient activation for self-management and to evaluate whether these are disease-transcending.

Methods A cross-sectional survey study was conducted in primary and secondary care in patients with type-2 Diabetes Mellitus (DM-II), Chronic Obstructive Pulmonary Disease (COPD), Chronic Heart Failure (CHF) and Chronic Renal Disease (CRD). Using multiple linear regression analysis, we analyzed associations between self-management activation (13-item Patient Activation Measure; PAM-13) and a wide range of socio-demographic, clinical, and psychosocial determinants. Furthermore, we assessed whether the associations between the determinants and the PAM were disease-transcending by testing whether disease was an effect modifier. In addition, we identified determinants associated with low activation for self-management using logistic regression analysis.

Results We included 1154 patients (53% response rate); 422 DM-II patients, 290 COPD patients, 223 HF patients and 219 CRD patients. Mean age was 69.6 ± 10.9 . Multiple linear regression analysis revealed 9 explanatory determinants of activation for self-management: age, BMI, educational level, financial distress, physical health status, depression, illness perception, social support and underlying disease, explaining a variance of 16.3%. All associations, except for social support, were disease transcending.

Conclusion This study explored factors associated with varying levels of activation for self-management. These results are a first step in supporting clinicians and researchers to identify subpopulations of chronic disease patients less likely to be engaged in self-management. Increased scientific efforts are needed to explain the greater part of the factors that contribute to the complex nature of patient activation for self-management.

Introduction

A rising problem in health care is the growing number of people with one or more chronic conditions¹. Chronic conditions are associated with a higher mortality and a lower quality of life². The growing number of chronic disease patients places a huge burden on our health care systems. A promising strategy to address the burden on patients and society is self-management. Self-management refers to 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition'³.

In the last two decades, extensive scientific research on self-management has been performed and a wide range of self-management programs have been developed for various target populations. Results from meta-analyses show that self-management can improve quality of life, certain disease-specific outcomes and may reduce health care costs⁴⁻⁶. Although positive effects are seen in mean group outcomes, individual trials report that a substantial proportion of patients do not comply or respond to these interventions. This is demonstrated by the highly inconsistent outcomes in five clinical trials evaluating effectiveness of an almost identical self-management program in COPD patients ranging from highly successful to even harmful^{7,8}.

Little is known about characteristics distinguishing patients most likely to benefit from a self-management program. A first step in understanding variance in effect size is to identify factors associated with the degree to which patients are activated for self-management. Previous studies have identified several factors related to self-management behavior such as age⁹, gender⁹, education level¹⁰, multi-morbidity⁹, depression and anxiety^{9,11,12}, disease characteristics¹⁰, illness perception¹², social support¹³, disease duration, disease severity⁹, low socio-economic-status¹⁴ and health literacy¹⁴. These studies used highly varying methodologies and mainly focused on disease-specific parameters. We hypothesize that a substantial number of factors associated with levels of activation for self-management are disease-transcending instead of disease-specific, as many patients suffer from more than one chronic condition¹⁵. Previous studies analyzed only a limited number of factors simultaneously; ignoring a broader spectrum of disease and patient characteristics. Increased understanding of (disease-transcending) factors associated with activation for self-management is an essential first step towards tailored strategies.

This study aims to identify determinants of activation for self-management in patients with chronic diseases, i.e. patients with Chronic Obstructive Pulmonary Disease (COPD), Chronic Heart Failure (CHF), Diabetes Mellitus type II (DM-II) and Chronic Renal Disease (CRD). Furthermore, this study aims to identify variables associated with chronic disease patients at highest risk for low activation for self-management and to investigate whether these associations are disease-transcending.

Materials and Methods

Design and study population

A descriptive cross-sectional study was conducted to examine the association between determinants and outcome in four patient populations (COPD, CHF, DM-II and CRD). These diseases were selected as they are among the most prevalent in clinical practice and a substantial part of the disease progression and its burden can be delayed or partially prevented if patients engage in proactive management of their disease. Both determinants and outcome were assessed in a single questionnaire combined with chart review.

The study population consisted of adult patients living in the Netherlands with a clinical diagnosis of COPD, CHF, DM-II or CRD. Patients meeting the inclusion and exclusion criteria were recruited from six primary and four secondary care settings in different regions in the Netherlands. Inclusion criteria were adult patients with a clinical diagnosis of either COPD (age ≥ 40 , post-bronchodilator FEV1/FVC ratio $< 70\%$), CHF (confirmed by clinical signs and symptoms and documented by a cardiologist), DM-II (fasting plasma glucose ≥ 7.0 mmol/l or 2h plasma glucose ≥ 11.1 mmol/l) or CRD (Glomerular Filtration Rate < 60 mL/min/1.73m²). Exclusion criteria were being unable to speak, read, and write Dutch, conditions that could affect validity of the study (e.g. cognitive impairment), and having any kind of terminal illness (life expectancy < 3 months).

Procedure/Ethics

Eligible patients were selected by chart review according to the inclusion and exclusion criteria. Patients received an invitation letter from their attending physician to participate in this study with the attached study information that explained determinants that were to be assessed as part of the study, an informed consent form and a questionnaire. Patients were asked to sign the informed consent form and to complete the questionnaire and return it to the research team. Patients were enrolled when both documents were received and subsequently chart review was performed. Patients who did not respond to the initial invitation received a reminder after three weeks. Permission for the study was granted by the medical ethical committee of the University Medical Center Utrecht.

Outcome measure

The primary outcome was activation for self-management, which was assessed with the 13-item Patient Activation Measure (PAM-13). The PAM was considered the best generic measure, since it assesses self-reported knowledge, skills and confidence for self-management irrespective of the underlying chronic condition¹⁶. The PAM-13 has shown to be associated with a range of self-management behaviors (e.g. exercising and disease specific behaviors)^{16,17}. A positive change in activation is related to a positive change in various self-management behaviors^{18,19}.

The PAM-13 is validated and translated into Dutch and has shown to be internally consistent ($\alpha=0.88$) with item-rest correlations varying from moderate to strong²⁰. Answers are given on a five-point scale. The scores on each item are summed to give an overall raw score, this score is converted into a theoretical 0-100 point scale according to the PAM's scoring table²¹. The PAM-13 makes a distinction among four activation levels associated with increasing self-management engagement. Based on cut-off points a person can be divided into level 1 (≤ 47.0 points), level 2 (47.1-55.1 points), level 3 (55.2-67 points) and level 4 (≥ 67.1 points) [17]. Level 1 includes the lowest activation scores corresponding to patients with low self-management engagement. These patients are not taking an active role in self-management and thus considered passive recipients of care¹⁶.

Determinants

Determinants of activation for self-management were assessed using various scales, surveys, sociodemographic and disease characteristics.

Health status was assessed using the Short Form-12 Health Survey (SF-12)²², which is a shorter version of the Short Form-36 (SF-36)²³. The SF-12 measures physical and mental health by means of two summary scores on a scale of 0-100. Higher scores on the SF-12 are related to a better health status. Results of the SF-12 and SF-36 showed almost complete overlap²⁴.

Anxiety and depression were measured with the Hospital Anxiety and Depression Scale (HADS)²⁵. This is a 14-item self-reported screening instrument used as an indicator for the presence of anxiety or depression in general medical patients. The HADS includes two 7-item scales: one for anxiety and one for depression, both with a score range of 0-21. A higher rating indicates a higher state of anxiety or depression. A score ≥ 11 suggests the presence of an anxiety or depressive disorder. The HADS was validated in different groups of Dutch subjects²⁶.

Illness perception was measured with the Brief Illness Perception Questionnaire (B-IPQ) consisting of eight items that can be scored on a scale from 1-10. An overall score can be computed (scores range from 0 – 80) with a higher score reflecting a more threatening view of the disease. The B-IPQ was validated and translated into Dutch²⁷. Face and content validity were found to be acceptable. Reproducibility showed moderate to good reliability²⁷.

Social support was assessed with the Multidimensional Scale of Perceived Social Support (MSPSS). This is a 12-item scale that was used to measure perceived social support²⁸. The scale focuses on support from family, friends, and significant others. Items were scored on a 7-point Likert scale. Higher scores meant higher perceived support. The validity and reliability of the Dutch version MSPSS was confirmed in a group of Dutch cardiac patients and their partners²⁹.

Sociodemographic characteristics included age, gender, and ethnicity operationalized as Dutch versus any other nationality. Educational level, financial distress and a surrogate for income, namely receiving care allowance were measured to get an indication of socio-economic status. Educational level was divided into lower (primary school through vocational training), medium (secondary school or vocational training) and higher (college or university degree) education. Financial distress was defined as none, low or high distress. Receiving care allowance was operationalized as having a single annual income < €30,939 or a combined annual income < €42,438³⁰.

Disease characteristics included severity and duration. Indicators of disease severity were operationalized by the stage of the disease (Table 1). Disease duration was divided in <2 years, 2-5 years or >5 years from diagnosis. The impact of comorbidities was assessed using the Charlson Comorbidity Index³¹. This index is based on relative risks of mortality, in which ICD-10 conditions were assigned with values of 1, 2, 3, or 6 (all other conditions are given a score of 0)³². Comorbidities were extracted by chart review, the assigned values were then summed for each patient to create a total score.

Table 1. Operationalization of disease severity

Disease severity	DM-II	COPD	CHF	CRD
Mild	No medication	GOLD 1	NYHA 1	GFR 40-59 ml/min
Moderate	Only oral medication	GOLD 2 + 3	NYHA 2 + 3	GFR 15-39 ml/min
Severe	Use of insulin	GOLD 4	NYHA 4	GFR <15ml/min

DM-II= Diabetes mellitus type 2, COPD= Chronic obstructive pulmonary disease, CHF= Chronic Heart Failure, CRD= Chronic renal failure, GOLD = Global Initiative for chronic obstructive Lung Disease. NYHA = New York Heart Association. GFR = Glomerular Filtration Rate.

Data analysis

Analyses were performed using the SPSS Windows Version 20³³. Patient characteristics are presented as mean \pm standard deviation for continuous variables and number and percentages for categorical variables. Patients were excluded when the PAM-13 (dependent variable) had more than seven missing items or when all 13 questions were answered identically²¹. Following analysis of missing values of all independent variables, multiple imputation was performed since imputation of missing values may reduce bias when the values are missing at random³⁴. Ten imputed data-sets were created. Estimates for each data set were averaged to get a pooled estimate of the association. Statistical power was based on the rule of thumb of 10 events needed per variable³⁵.

Linear regression was performed to show the univariable determinant-outcome association and was not used as a selection method for candidate variables³⁶. A multiple linear regression analysis with a stepwise backward method was performed to identify variables associated

with activation for self-management. A p-value <0.20 was used for variable selection. This method was applied to each data set, resulting in 10 sets of selected variables. The final set comprised those variables that were selected in 50% or more of the 10 data sets³⁷. The pooled results are presented. We used Fisher's *r* to *z* transformation to calculate pooled R^2 statistics as suggested by Harel³⁸. The assumptions of linearity, homoscedasticity were checked and approved. A multiple correlation table was made of the studied determinants and the outcome and collinearity was considered when $r > 0.8$ (S1 Table). Since the assumption of normality was not completely met, generalized linear models were used with robust standard estimators in the linear regression analysis.

We assessed whether the associations between the determinants and activation were generic or disease specific by testing whether disease was an effect modifier. This was performed by comparing the *R* squared change of the final model with the same final model, but with the inclusion of an interaction term of one predictor variable with disease dummy variables. This procedure was repeated for all selected determinants. However, since patients could have more than one chronic disease under study and this could influence the results of this analysis we repeated this analysis in the subgroup of patients with only one studied disease.

To identify determinants associated with poor activation for self-management, PAM outcomes were dichotomized in patients in level 1 and patients in levels 2 – 4. Subsequently, a logistic regression analysis was performed and variables were identified using a similar methodology.

Results

Response and patient characteristics

A total of 2184 eligible patients were approached to participate in this study of which 1239 patients were willing to participate (Fig. 1). Of these patients, 31 patients were not eligible since they did not meet the inclusion and/or exclusion criteria. Another 54 patients produced invalid PAM-13 scores [21] and were, therefore, excluded. Data from 1154 patients (response rate 53%) were included in the final analysis. Of these 1154 patients, 422 (37%) were DM-II patients, 290 (25%) COPD patients, 223 (19%) CHF patients and 219 (19%) CRD patients. Of all participants, 60% were males and the age range was 28 – 92 years old with a mean age of 69.6 ± 10.9 . Almost 63% had more than 1 comorbid disease, and 30% of the patients had more than one of the four chronic diseases under study: 236 patients had 2, 97 patients had 3, and 13 patients had all four studied diseases. Patient characteristics and mean PAM-13 scores are described in Table 2. The percentage of total missing values was 2%; these missing values were distributed amongst 24% of our cases.

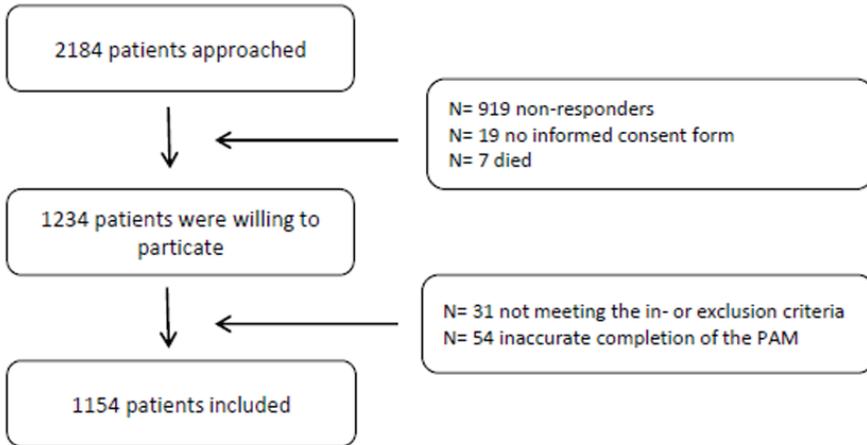


Figure 1. Flowchart of recruitment

Figure 2 shows the varying levels of self-management activation. Mean PAM-13 scores differed across the conditions: for DM-II the mean score was 55.3 ± 11.0 , for COPD 54.7 ± 10.4 , for CHF 53.6 ± 11.2 and for CRD 51.4 ± 10.0 . For each condition, only a minority of patients scored PAM level four.

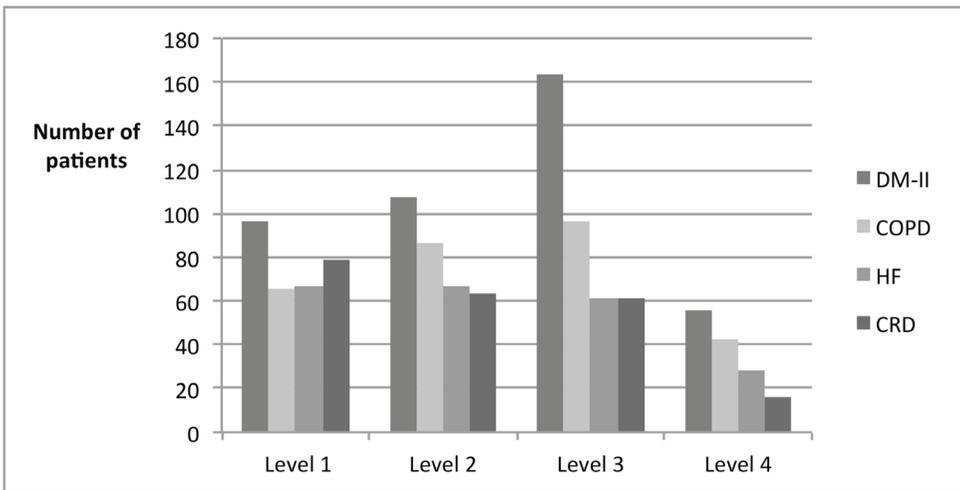


Figure 2. Distribution of PAM (patient activation measure) scores stratified by underlying chronic condition. DM-II = diabetes mellitus type 2, COPD= Chronic obstructive pulmonary disease, CHF= Chronic heart failure, CRD= Chronic renal disease.

Table 2. Patient characteristics of the combined and separate chronic disease population(s)

	<i>DM-II (n=422)</i>	<i>COPD (n=290)</i>	<i>CHF (n=223)</i>	<i>CRD (n=219)</i>	<i>Total (n=1154)</i>
Gender					
Male	241 (57.1%)	184 (63.4%)	134 (60.1%)	135 (61.6%)	694 (60.1%)
Female	181 (42.9%)	105 (36.2%)	88 (39.5%)	84 (38.4%)	458 (39.7%)
Age (years)	68.0 ± 10.8	67.2 ± 10.3	73.9 ± 9.8	71.7 ± 11.5	69.6 ± 10.9
Ethnicity					
Dutch	402 (95.3%)	268 (92.4%)	212 (95.1%)	204 (93.2%)	1086 (94.1%)
Other	16 (3.8%)	19 (6.6%)	7 (3.1%)	12 (5.5%)	54 (4.7%)
BMI (kg/m²)	28.6 ± 4.3	26.6 ± 4.7	26.6 ± 4.3	27.8 ± 4.8	27.6 ± 4.6
Living situation					
Living alone	104 (24.6%)	72 (24.8%)	81 (36.3%)	66 (30.1%)	323 (28.0%)
Living not alone	313 (74.2%)	213 (73.4%)	137 (61.4%)	146 (66.7%)	809 (70.1%)
Illness duration					
≤2 years	80 (19.0%)	42 (14.5%)	43 (19.3%)	57 (26.0%)	222 (19.2%)
2-5 years	111 (26.3%)	69 (23.8%)	43 (19.3%)	76 (34.7%)	299 (25.9%)
>5 years	230 (54.5%)	135 (46.6%)	111 (49.8%)	59 (26.9%)	535 (46.4%)
Illness severity					
Mild	82 (19.4%)	93 (32.1%)	52 (23.3%)	54 (24.7%)	281 (24.4%)
Moderate	266 (63.0%)	173 (59.7%)	147 (65.9%)	133 (60.7%)	719 (62.3%)
Severe	43 (10.2%)	14 (4.8%)	15 (6.7%)	32 (14.6%)	104 (9.0%)
Charlson comorbidity index	2.1 ± 1.4	2.5 ± 1.5	3.8 ± 2.1	4.2 ± 1.7	2.9 ± 1.8
Smoking					
Never	126 (29.9%)	25 (8.6%)	62 (27.8%)	63 (28.8%)	276 (23.9%)
Former	236 (55.9%)	173 (59.7%)	135 (60.5%)	123 (56.2%)	667 (57.8%)
Current	54 (12.8%)	89 (30.7%)	24 (10.8%)	29 (13.2%)	196 (17.0%)
Education					
Low	201 (47.6%)	126 (43.4%)	103 (46.2%)	100 (45.7%)	530 (45.9%)
Medium	153 (36.3%)	111 (38.3%)	78 (35.0%)	87 (39.7%)	429 (37.2%)
High	58 (13.7%)	46 (15.9%)	37 (16.6%)	27 (12.3%)	168 (14.6%)
Financial distress					
None	211 (50.0%)	121 (41.7%)	105 (45.7%)	104 (47.5%)	538 (46.6%)
Low	157 (37.2%)	129 (44.5%)	100 (44.8%)	95 (43.4%)	481 (41.7%)
High	39 (9.2%)	33 (11.4%)	13 (5.8%)	12 (5.5%)	97 (8.4%)
Care Allowance*					
Received	219 (51.9%)	119 (41.0%)	135 (60.5%)	115 (52.5%)	588 (51.0%)
Not received	197 (46.7%)	159 (54.8%)	78 (35.0%)	101 (46.1%)	535 (46.4%)
HADS					
Depression	4.6 ± 3.6	5.6 ± 4.1	5.6 ± 4.0	5.1 ± 3.8	5.1 ± 3.9
Anxiety	4.3 ± 3.6	5.7 ± 4.3	5.4 ± 4.0	4.5 ± 3.6	4.9 ± 3.9
Health status (SF-12)					
Physical	60.9 ± 25.6	45.6 ± 24.5	40.7 ± 24.8	49.9 ± 26.6	51.1 ± 26.3
Mental	69.8 ± 23.0	61.7 ± 23.4	59.7 ± 24.8	66.2 ± 23.1	65.2 ± 23.4
Illness perception (B-IPQ)	30.6 ± 11.6	40.1 ± 12.0	40.7 ± 11.2	37.8 ± 12.7	36.3 ± 12.7
Social support (MSPSS)	62.6 ± 15.0	60.6 ± 17.4	65.0 ± 15.0	64.0 ± 15.5	62.8 ± 15.8
Comorbidity DM		29 (10.1%)	67 (30.2%)	76 (34.7%)	
Comorbidity COPD	38 (9%)		42 (18.9%)	36 (16.4%)	
Comorbidity CHF	17 (4%)	14 (4.8%)		39 (17.8%)	
Comorbidity CRD	25 (5.9%)	9 (3.1%)	76 (34.2%)		
Activation (PAM-13)	55.3 ± 11.0	54.7 ± 10.4	53.6 ± 11.2	51.4 ± 10.0	54.1 ± 10.8

Data are presented as n,% or mean ± SD. DM-II = Diabetes Mellitus type II, COPD = Chronic obstructive Pulmonary Disease, CHF = Chronic Heart Failure, CRD = Chronic Renal Failure, BMI = Body Mass Index, HADS = Hospital Anxiety and Depression Scale, SF-12 = 12-item Short-form health survey, B-IPQ = Brief Illness Perception Questionnaire, MSPSS = Multidimensional Scale of Perceived Social Support, PAM-13 = 13-item Patient Activation Measure.* Care allowance received by single people making an annual living < €30,939 or a combined annual living < €42,438.

Identifying variables associated with activation for self-management

Results of the univariable and multiple linear regression analyses are shown in Table 3. The explained variance (R^2) of the full multivariable linear model was 0.17. Reducing the model by backward selection to a model with nine variables did not substantially change the explained variance (R^2 0.16). Variables associated with self-management activation in the final reduced multivariable model were age, BMI, education level, financial distress, physical health status, depression, illness perception, social support and chronic condition.

Table 3. Linear regression analyses – univariable associations of the determinants with activation for self-management.

	Univariable linear regression	
	Unstandardized coefficients (95% CI)	Standardized coefficients
Age (years)	-0.07 (-0.12;-0.01)	-0.07
Gender (female vs male)	-0.87 (-2.14; 0.40)	-0.04
BMI (kg/m ²)	-0.33 (-0.46;-0.19)	-0.14
Ethnicity (non-native vs native)	-2.86 (-5.81; 0.09)	-0.06
Level of education		
Moderate vs low	0.17 (-1.18; 1.53)	0.01
High vs low	4.41 (2.56; 6.26)	0.15
Living together vs alone	1.37 (0.01;2.75)	0.06
Smoking		
Former vs never	0.35 (-1.17; 1.86)	0.02
Current vs never	-0.55 (-2.53; 1.43)	-0.02
Financial distress		
Low vs none	-3.46 (-4.77;-2.15)	-0.16
High vs none	-4.29 (-6.58;-2.00)	-0.11
Receiving care allowance (y/n)	-0.87 (-2.12; 0.39)	-0.04
Charlson comorbidities index	-0.83 (-1.16;-0.49)	-0.14
Severity of disease		
Moderate vs mild	-2.94 (-4.41;-1.48)	-0.13
Severe vs mild	-3.21 (-5.68;-0.74)	-0.09
Duration of disease		
2-5 yrs vs ≤2 yrs	1.04 (-0.81;2.88)	0.04
>5 yrs vs ≤2 yrs	0.17 (-1.48;1.83)	0.01
Health status (SF-12)		
Physical component	0.11 (0.09;0.13)	0.26
Mental component	0.11 (0.09;0.14)	0.24
HADS (Hospital anxiety and depression scale)		
Anxiety	-0.51 (-0.67;-0.36)	-0.19
Depression	-0.70 (-0.86;-0.55)	-0.25
Illness perception	-0.24 (-0.29;-0.19)	-0.28
Social support	0.12 (0.08;0.16)	0.18
Chronic disease		
COPD vs DM-II	-0.60 (-2.20;1.00)	-0.02
CHF vs DM-II	-1.73 (-3.47;0.01)	-0.06
CRD vs DM-II	-3.98 (-5.72;-2.23)	-0.14

CI= Confidence interval, BMI= Body Mass Index, DM-II = Diabetes Mellitus type II, COPD = Chronic Obstructive Pulmonary Disease, CHF= Chronic Heart Failure, CRD = Chronic Renal Failure.

Furthermore, we explored whether the associations between the determinants and activation were disease-transcending or disease-specific. All determinants in the final model, except social support, were associated with the PAM-13 irrespective of the underlying chronic condition. The relation between social support and activation differed per condition. In comparison to DM-II, there was a small negative interaction between social support and condition, particularly for COPD (model including COPD as interaction term: -0.12, 95%CI -0.21 to -0.03). This means that the association between COPD and activation is also dependent on social support. In the analysis in the subgroup of patients with only one studied condition (n=806) we only found the same interaction for COPD and social support (S2 Table).

Table 4. Linear regression analyses – multivariable associations of the determinants with activation for self-management.

	Final multiple linear regression model after reduction		Final multiple regression model +interaction term disease*social support	
	Unstandardized coefficients (95% CI)	Standardized coefficients	Unstandardized coefficients (95% CI)	Standardized coefficients
Age (years)	-0.04 (-0.10; 0.02)	0.04	-0.05 (-0.11; 0.01)	-0.05
BMI (kg/m ²)	-0.24 (-0.37;-0.11)	-0.10	-0.24 (-0.38;-0.10)	-0.10
Level of education				
Moderate vs low	-0.57 (-1.81; 0.68)	-0.03	-0.40 (-0.17;0.90)	-0.02
High vs low	1.93 (0.10; 3.76)	0.06	2.02 (0.22;3.81)	0.07
Financial distress				
Low vs none	-1.72 (-2.98;-0.47)	-0.08	-1.67 (-2.95;-0.39)	-0.08
High vs none	-1.18 (-3.50; 1.15)	-0.03	-1.16 (-3.45;1.12)	-0.03
Health status (SF-12)				
Physical component	0.03 (-0.00;0.07)	0.08	0.03 (0.00;0.06)	0.08
HADS (Hospital anxiety and depression scale)				
Depression	-0.15 (-0.35;0.04)	-0.05	-0.14 (-0.34;0.06)	-0.05
Illness perception	-0.16 (-0.21;-0.10)	-0.19	-0.16 (-0.22;-0.10)	-0.19
Social support	0.09 (0.05;0.13)	0.13	0.15 (0.08;0.21)	0.21
Chronic disease				
COPD vs DM-II	1.35 (-0.23;2.94)	0.05	8.62 (2.73;14.51)	0.35
CHF vs DM-II	0.29 (-1.52; 2.10)	0.01	0.70 (-0.65;7.91)	0.03
CRD vs DM-II	-2.45 (-4.09;-0.81)	-0.09	3.31 (-3.73;10.35)	0.12
Social support* COPD vs DM-II			-0.12 (-0.21;-0.03)	-0.30
Social support* CHF vs DM-II			-0.01 (-0.12;0.10)	-0.02
Social support* CRD vs DM-II			-0.09 (-0.20;0.02)	-0.22
Explained variance of the model	R ² = 0.16, adjusted R ² = 0.15		R ² = 0.17, adjusted R ² = 0.16	

CI= Confidence Interval, BMI= Body Mass Index, DM-II = Diabetes Mellitus type II, COPD = Chronic Obstructive Pulmonary Disease, CHF= Chronic Heart Failure, CRD = Chronic Renal Failure.

Identifying patients at highest risk for poor activation for self-management

Table 4 shows results of the logistic regression analysis. Poor activation was associated with having a higher BMI, more financial distress, a higher comorbidity index score, a medium education level, a shorter disease duration, a more negative illness perception, living alone and being depressed.

Table 5. Multivariable logistic regression analyses – determinants associated with poor activation for self-management.

	Multivariable logistic regression OR (95% CI)
BMI (kg/m²)	1.05 (1.01; 1.08)
Living alone vs together	1.50 (1.10; 2.06)
Financial distress	
Low vs none	1.60 (1.17; 2.18)
High vs none	1.63 (0.98; 2.72)
Charlson comorbidities index	1.10 (1.00; 1.20)
Education level	
Moderate vs low	1.41 (1.03; 1.92)
High vs low	0.78 (0.47; 1.30)
Duration of disease	
2-5 yrs vs ≤2 yrs	0.67 (0.44; 1.02)
>5 yrs vs ≤2 yrs	0.66 (0.45; 0.96)
Physical Health status (SF-12)	0.99 (0.99; 1.00)
HADS depression	1.05 (1.01; 1.10)
Illness perception	1.03 (1.01; 1.04)
Social support	0.99 (0.98; 1.00)
Chronic disease	
COPD vs DM-II	0.67 (0.44; 1.01)
CHF vs DM-II	0.88 (0.56; 1.39)
CRD vs DM-II	1.27 (0.81; 2.00)
Nagelkerke R ² =0.20	

CI= Confidence interval, OR= Odds ratio, CI= confidence interval, BMI= Body mass index, SF-12= short form-12, HADS= Hospital anxiety and depression scale, DM-II = Diabetes Mellitus type II, COPD = Chronic Obstructive Pulmonary Disease, CHF= Chronic Heart Failure, CRD = Chronic Renal Failure.

Discussion

This study aimed to identify variables associated with patient activation for self-management in combined chronic disease populations. In total, nine explanatory variables were found to be mildly associated with activation: age, BMI, education level, financial distress, physical health status, depression, illness perception, social support and disease. Although many variables were taken into account, the multiple linear regression model explained only 16% of the variance in self-management activation, which means that 84% remains unexplained. All variables in the model, except social support, were found to be disease-transcending.

Furthermore, variables associated with chronic disease patients at highest risk for poor activation for self-management were explored. These variables were BMI, living alone, education level, financial distress, comorbidity index score, disease duration, depression, and illness perception. In this model most factors are the same, however living alone, comorbidity index score and disease duration are solely associated with poor activation. The distribution in PAM levels showed that only a minority of the patients were in PAM level four and half of the patients were in level one and two, which suggests there is considerable room for improvement in activation for self-management in these patients. In this study, the mean scores on the PAM-13 are lower compared to another Dutch study by Rademaker et al, 54.1 vs 61.3²⁰. This might be explained by differences in patient population, such as a substantially lower age (59 vs 70 in the current study).

Previous studies have described several personal factors that influence (activation for) self-management. Most factors in this study are in line with other papers. Most studies investigated patients with one specific disease with fewer patient characteristics^{10,14,39}. Previous studies using the PAM-13 showed that female patients, with a relatively younger age, a higher education level and a better self-reported health had higher PAM-13 scores¹⁶. The same associations were described by Rademaker et al. in a Dutch sample, except that male gender, instead of female, was associated with a higher PAM-13 score²⁰. In this study, gender was not associated with PAM-13 scores; the other associations were similar. In line with our study, Hibbard et al. found that having depressive symptoms is related to a lower PAM-13 score¹⁶.

This study aimed to identify variables independently associated with activation for self-management. Although we studied a large number of variables, only 16% of the variance could be explained. This is in line with the study of Rockwell et al. reporting a low explained variance of 10.3%¹⁰. Rockwell et al. tested a model of seven patient characteristics in CHF patients and found that only two characteristics were positively associated with self-management of heart failure; a higher education level and increased disease severity. In

this study, disease severity did not remain in the model as an explanatory variable. Another CHF study explained 38% of the variance of self-care management⁹ with the following four variables: gender, moderate-to-severe comorbidity, depression, and self-care confidence. They found that male gender and moderate-to-severe comorbidity index was associated with higher self-care scores. In our study, patients with a higher comorbidity index had lower levels of activation for self-management. The differences in identified determinants and explained variance could possibly be explained by the large heterogeneity in outcome measures and the chosen selection of variables.

With a composition of 19 disease- and patient specific variables in the model, we expected to explain a greater amount of the variance in the PAM-13 score. However, linear associations of variables and PAM-13 were low. It can be concluded that engagement in self-management is a complex and perhaps even diffuse behavior not easy to grasp with straightforward disease- and patient parameters. An important finding is that the associations found were disease-transcending, which means that their impact on varying levels of activation for self-management is not modified by the underlying chronic condition. The main question remaining is which factors can explain the remaining 84% in our model. According to Bandura's social cognitive theory⁴⁰, individuals are most likely to engage in a health behavior if they are confident in their ability to perform the behavior, in other words self-efficacy. Self-efficacy was not included in this analysis because self-efficacy items are included in the PAM-13. The Transtheoretical Model of behavioral change, as described by Prochaska et al., was used to develop the PAM-13⁴¹. This model emphasizes motivation and readiness to move forward on the different stages of change. Motivation is a frequently mentioned factor facilitating self-management engagement in qualitative research^{42,43}. However, we did not measure motivation as a separate variable. Motivation and self-efficacy could have contributed to explain the remaining variance. Other factors that we did not incorporate into our model and that could have contributed are health literacy²⁰ and cognitive impairment⁴⁴, since they have shown to be associated with activation for self-management.

A strength of this study is the large sample size and the relatively high response rate. Furthermore, the sample consisted of four different chronic disease populations, and we included patients from primary and secondary care settings, thus creating a wide range in disease severity.

A limitation is the use of self-reported questionnaires which might have introduced misclassification due to patients' tendency to provide social desirable answers and may, therefore, have led to underestimation of effects. Due to the cross-sectional design, no conclusions can be drawn on the cause and effect of the associations. Furthermore, as a result of the survey design, we could not include all potential important determinants.

Patients with cognitive impairment were excluded because these impairments may lead to less valid answers on the questionnaire. Furthermore, few non-native patients were included, which is probably due to the language barrier to fill out a questionnaire.

By trying to find generic variables across four chronic diseases a generic questionnaire, the PAM-13, was chosen as a measure for activation for self-management. We considered this tool to be the best available method to evaluate the complexity of activation for self-management in different target populations.

Future longitudinal studies are needed to investigate whether the identified variables can be used to identify subgroups of patients with barriers to engage in self-management. Future studies should evaluate the importance of other factors, such as cognitive impairment, health literacy, motivation and self-efficacy with regard to self-management activation. Additionally, scientific efforts are needed to investigate causal pathways between these determinants and activation. This knowledge might help healthcare professionals to identify patients at risk of inadequate self-management behaviors, which is essential for the development of more individually targeted and tailored interventions.

Conclusions

This study increases the understanding about the distribution of activation for self-management in a large population of chronic disease patients. Irrespective of the underlying condition, a substantial part of patients register low PAM scores, indicating poor levels of activation. The results show that age, BMI, education level, financial distress, physical health status, depression, illness perception, social support and disease are associated with activation for self-management and that BMI, living alone, education level, financial distress, comorbidity index score, disease duration, depression and illness perception are associated with poor self-management engagement. As expected, most variables in the model were disease-transcending, except social support. This knowledge is a first step in helping health care providers to identify subpopulations of chronic disease patients that are less likely to be engaged in self-management activities which is essential to move towards targeting and tailoring of self-management interventions. However, we are still a long way from explaining the greater part of factors that contribute to the complex nature of self-management behavior.

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Supporting Information

S1 Table. Multiple correlation table. HADS= Hospital Anxiety and Depression Scale, COPD=Chronic Obstructive Pulmonary disease. * p-value <0.01

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	
1 Activation	1																							
2 Gender	-0.04	1																						
3 Age	-0.07	0.00	1																					
4 Ethnicity	-0.06	-0.05	-0.11*	1																				
5 Body mass index	-0.14*	0.04	-0.13*	0.03	1																			
6 Living situation	0.06	-0.18*	-0.20*	0.04	0.01	1																		
7 Illness duration	-0.00	0.00	0.13*	-0.02	0.04	-0.06	1																	
8 Illness severity	-0.11*	-0.03	0.06	0.08*	0.02	-0.03	0.23*	1																
9 Charlson comorbidity index	-0.14*	-0.08*	0.34*	-0.04	0.01	-0.14*	0.07	0.11*	1															
10 Smoking	-0.01	-0.17*	-0.13*	-0.01	-0.08*	0.02	-0.08	0.00	0.02	1														
11 Education	0.11*	-0.16*	-0.11*	0.00	-0.12*	0.04	0.00	-0.07	-0.06	0.09	-0.21	1												
12 Financial distress	-0.16*	0.06	-0.11*	0.18*	0.17*	-0.05	0.03	0.06	0.06	0.09	-0.21	1												
13 Care allowance	-0.04	0.04	0.04	0.03	0.05	0.14	0.04	0.03	0.08	-0.04	0.00	0.05	1											
14 HADS Depression	-0.25*	0.07	0.11*	0.18*	0.07	-0.06	0.04	0.15*	0.20*	0.00	-0.19*	0.27*	0.08*	1										
15 HADS anxiety	-0.18*	0.15*	0.03	0.17*	0.04	-0.11*	0.01	0.12*	0.14*	0.03	-0.12*	0.25*	0.05	0.66*	1									
16 Physical health status	0.26*	-0.15*	-0.22*	-0.10*	-0.12*	0.15*	-0.08	-0.22*	-0.33*	0.01	0.12*	-0.24*	-0.07	-0.56*	-0.48*	1								
17 Mental health status	0.24*	-0.23*	-0.11*	-0.14*	-0.08*	0.14*	-0.06	-0.20*	-0.22*	0.02	0.14*	-0.26*	-0.08	-0.71	-0.67*	0.75*	1							
18 Illness perception	-0.28*	0.03	0.00	0.14*	0.01	-0.04	0.06	0.22*	0.16*	0.03	-0.10*	0.18*	0.03	0.49*	0.43*	-0.53*	-0.51*	1						
19 Social support	0.18	-0.05	-0.01	-0.07	-0.03	0.19*	0.01	0.04	0.03	-0.04	-0.01	-0.10*	0.04	-0.25*	-0.20*	0.13*	0.21*	-0.12*	1					
20 Diabetes mellitus type 2	0.00	-0.00	0.03	0.01	0.26*	-0.02	0.09*	0.12*	0.05	-0.12*	-0.05	0.02	0.12	-0.05*	-0.09*	0.13*	0.08*	-0.26*	-0.03	1				
21 COPD	0.00	-0.08	-0.04	0.03	-0.09*	-0.00	0.05	-0.06	0.08*	0.31*	-0.01	0.09	-0.06	0.10*	0.13*	-0.20*	-0.13*	0.20*	-0.06	-0.39*	1			
22 Heart failure	-0.06	-0.01	0.26*	-0.03	-0.08	-0.09	0.02	0.04	0.38*	-0.09*	-0.01	0.02	0.12*	0.10*	0.07	-0.24*	-0.13*	0.16*	0.10*	-0.19*	-0.14*	1		
23 Chronic renal disease	-0.14*	-0.03	0.22*	-0.01	0.01	-0.08	-0.08*	0.08*	0.57*	-0.08	-0.02	-0.03	0.05	0.05	-0.00	-0.13*	-0.05	0.12*	0.07	-0.12*	-0.19*	0.17*	1	

S2 Table. Linear regression analyses – multivariable associations of the determinants with activation for self-management in patients with no comorbid study diseases. CI= Confidence interval, BMI= Body Mass Index, DM-II = Diabetes Mellitus type II, COPD = Chronic Obstructive Pulmonary Disease, CHF= Chronic Heart Failure, CRD = Chronic Renal Failure.

N=806	Final multiple linear regression model after reduction		Final multiple regression model +interaction term disease*Social support	
	Unstandardized coefficients (95% CI)	Standardized coefficients	Unstandardized coefficients (95% CI)	Standardized coefficients
BMI (kg/m²)	-0.14 (-0.31;0.03)	0.06	-0.13 (-0.30;0.04)	-0.05
Level of education				
Moderate vs low	0.40 (-1.14; 1.94)	0.02	-0.63 (-0.91;2.17)	0.03
High vs low	3.30 (1.22; 5.37)	0.11	3.45 (1.38; 5.53)	0.12
Financial distress				
Low vs none	-1.40 (-2.92; 0.12)	-0.07	-1.33 (-2.85;0.19)	-0.06
High vs none	-1.16 (-3.907; 1.56)	-0.03	-0.95 (-3.68;1.77)	-0.03
Health status (SF-12)				
Physical component	0.05 (0.01;0.08)	0.11	0.04 (0.11;0.08)	0.11
Illness perception	-0.15 (-0.22;-0.08)	-0.18	-0.15 (-0.22;-0.08)	-0.18
Social support	0.09 (0.05;0.14)	0.14	0.16 (0.09;0.24)	0.24
Chronic disease				
COPD vs DM-II	1.79 (-0.14;3.59)	0.08	10.47 (4.03;16.91)	0.45
CHF vs DM-II	0.97 (-1.37; 3.32)	0.03	3.19 (-6.76; 13.13)	0.10
CRD vs DM-II	-1.72 (-3.93;0.94)	-0.06	3.36 (-6.20;12.93)	0.11
Social support* COPD vs DM-II			-0.14 (-0.24;-0.41)	-0.39
Social support* CHF vs DM-II			-0.04 (-0.19;0.11)	-0.08
Social support* CRD vs DM-II			-0.08 (-0.23; 0.06)	-0.18
Explained variance of the model	R ² = 0.14, adjusted R ² =0.13		R ² = 0.15, adjusted R ² =0.13	



3

Tailoring of self-management interventions in patients with heart failure

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Abstract

The effectiveness of Heart Failure (HF) self-management interventions varies within patients suggesting that one-size-does-not-fit-all. It is expected that effectiveness can be optimized when interventions are tailored to individual patients. The aim of this review was to synthesize the literature on current use of tailoring in self-management interventions, and patient characteristics associated with self-management capacity and success of interventions, as building blocks for tailoring.

Within available trials, the degree to which interventions are explicitly tailored is marginal and often limited to content. We found that certain patient characteristics that are associated with poor self-management capacity do not influence effectiveness of a given intervention (i.e. age, gender, ethnicity, disease severity, number of comorbidities) and that other characteristics (low: income, literacy, education, baseline self-management capacity) in fact are indicators of patients with a high likelihood for success. Increased scientific efforts are needed to continue unraveling success of self-management interventions and to validate the modifying impact of currently known patient characteristics.

Introduction

Heart failure (HF) is a major health problem^{1,2}, characterized by a wide spectrum of debilitating symptoms, poor quality of life, frequent hospitalizations, and high mortality^{3,4}. Outcomes have improved over the last two decades for those with HF and a reduced ejection fraction with pharmacological therapy, devices and multidisciplinary management programs^{3,5}.

A part of the progression of HF and its burden on patients and society is thought to be preventable if patients are engaged in the (proactive) management of their disease^{6,7}. Patients who are actively involved in their care and who have the competences to adhere to treatment regimens and take appropriate actions are expected to have better survival and reduced hospital (re-)admissions⁸⁻¹⁰. In the literature the terms self-management, self-maintenance, and self-care sometimes are used as separate terms¹¹ and sometimes used interchangeably to cover the complex challenges patients face in coping with their disease¹². To enhance the readability and to remain consistent with international chronic care models¹³, we will use the term self-management throughout this review. The key targeted HF self-management competences are: i) adherence to complex medication regimens, ii) monitoring symptoms and taking appropriate action when needed and iii) compliance with exercise, dietary, and other lifestyle recommendations¹⁴.

Over the past decades many interventions have been developed and evaluated that may help to equip patients with these complex self-management competences. Most interventions provided (nurse-led) patient education and training skills to support self-management¹⁵. Several meta-analyses have highlighted the heterogeneity in delivery, methods and duration of these interventions. Reviews including studies that evaluated isolated educational interventions showed improvements in knowledge^{16,17}. When self-management was studied as part of more comprehensive disease-management or telehealth program, more robust results were reported, such as reduction of disease-related hospital admissions¹⁸⁻²³, mortality^{18,19,22} and improved health-related quality of life (HRQoL)²⁴. One meta-analysis calculated the pooled results of isolated self-management interventions and found a reduction in HF and all-cause hospitalizations and improved medication adherence but not in mortality, HRQoL, functional capacity or symptoms²⁵. The results from the aforementioned reviews indicate that the evidence for effectiveness of self-management interventions is ambiguous. This may be partly due to mixed quality of the reviews²⁶, heterogeneity in program and patient characteristics²⁷ and low treatment fidelity of the provider²⁸.

There is a need to better understand the key elements of successful self-management interventions. An important starting point is recognizing that managing a complex multi-impact disease is difficult. This is supported by several studies showing that self-management capacity in patients with HF is generally poor²⁹⁻³². Pooled results from 15 countries indicated that poor uptake of self-management is a worldwide phenomenon³³.

Besides variations in self-management capacity, longitudinal studies have shown that patient-specific characteristics also seem to modify the effectiveness of self-management interventions. Meta-analytical findings have indicated that a substantial number of patients do not or insufficiently respond to self-management interventions^{25,34}. The current premise that some interventions work better in specific patient populations suggests and not in others suggest that one-size-does-not-fit-all^{27,35}, in other words: more tailored approaches will be needed.

In a tailored approach, the treatment exposure is dynamic instead of the more fixed exposure in one-size-fits-all interventions³⁶. In a tailored intervention the individual is assessed and the intervention is customized based on the unique characteristics of that person, in order to increase the relevance of treatment and to produce greater desired changes³⁷. Customization refers to the personalized treatment consequence, such as variations in content (topics), behaviour change techniques, mode of delivery and dose³⁸. A specific type of tailoring is targeting in which subgroup characteristics are used to develop a single intervention for a defined population subgroup³⁶.

To optimize tailoring of interventions in HF, a thorough understanding of effective intervention ingredients is required, as well as knowledge of tailoring strategies and subgroups of patients in which a given self-management intervention is most effective. The aims of this review are (1) to describe the current use of tailoring in self-management interventions in patients with HF and to synthesize the essential literature on patient characteristics associated with (2) self-management capacity and (3) intervention effects.

Current use of tailored self-management approaches in clinical trials

Recently, we established a large international collaboration between principal investigators of HF self-management trials³⁵. The aim of this consortium is to unravel success of self-management interventions through pooling and modeling individual patient data (IPD) in a meta-analysis of previously conducted randomized clinical trials. The search and selection strategy applied in the IPD meta-analysis has been described in detail elsewhere³⁵. Self-management interventions were operationalized as patient-focused interventions with at least two of the following components: (1) active stimulation of symptom monitoring, (2) education in problem solving skills (i.e. self-treatment such as managing acute exacerbations, resource utilization and stress/symptom management) and enhancement of either (3) medication adherence, (4) physical activity, (5) dietary intake or (6) smoking cessation. For this review we used a similar search strategy of the ongoing IPD meta-analysis and updated the study selection (until January 2015)³⁵.

Data on presence and type of tailoring were extracted for 52 self-management interventions. Tailoring was considered present if the intervention was personalized, based on an assessment of individual characteristics. Table 1 provides an overview of the tailoring strategies in HF self-management interventions and the theory underlying the tailored intervention. Of the 52 selected studies, 28 explicitly described their tailoring strategy. The sample size of the studies ranged from 40 to 715 and the majority were nurse-led interventions. Studies not included in table 1 were either not tailored or the investigators did not explicitly report their tailoring strategy³⁹⁻⁶². This includes studies in which the content might have been individualized to some extent but no clear description was provided on how this was applied. For example, in interventions with face-to-face consultations, interpersonal communication, goal setting, and problem solving could have resulted in individualization of the intervention; but this was not clearly reported in the publication.

Tailoring strategies

The 28 studies included a wide range of patient characteristics which guided tailoring of the content, dose or mode of the intervention. The most frequently mentioned were HF-related knowledge, self-management behaviors/skills (such as medication adherence, sodium intake, identify symptoms of deterioration, problem-solving), barriers for self-management, patient-reported needs and preferences. Other variables mentioned were environmental factors, health literacy, New York Heart Association (NYHA) class and activation level.

Tailoring was applied mostly with regard to content, thus addressing different topics based on the assessed patient characteristics. Six interventions customized on the mode of delivery, either changing the language⁶³⁻⁶⁶ or adapting the literacy level⁶⁷, and one study gave a choice in telephone or e-mail contact⁶⁸. Nine interventions varied contact frequency based on needs^{66,69-71}, NYHA-class^{72,73} or patients' preference^{63,65,68}. None of the studies reported on tailoring with regard to behavior change techniques.

We found five studies with an intervention designed for and targeted to a specific subgroup. Davis et al. targeted the intervention to HF patients with mild cognitive impairment by focusing on environmental manipulation (e.g. simplifying tasks) and training compensatory strategies (e.g. memory aids)⁷⁴. Barnason et al. targeted their intervention to HF patients at risk for impaired medication adherence (five or more routinely scheduled prescriptions)⁶⁷. Riegel et al.⁶⁶ adjusted a previous intervention to Hispanics by integrating cultural values and possibility of bilingual support. In two subsequent studies DeWalt et al. targeted their intervention to low literate patients, where the intervention was not only given to the subgroup of low literates but to all HF patients included in the trial^{63,75}.

Theoretical models underlying tailored interventions

In 14 of the tailored interventions, theoretical models were used as the underlying mechanism of the intervention, most often Bandura's social cognitive theory; particularly aiming at increasing patients' self-efficacy⁷⁶. In one single study, a theoretical model was

explicitly used for tailoring. Shively et al. used the activation theory to tailor the intervention based on patients' initial activation level as measured by the Patient Activation Measure (PAM)⁷⁷. Patients' baseline level of activation was assessed as low or medium to high and subsequently individualized goals for knowledge (low PAM) or skills and behaviors (medium and high PAM) were set⁷⁷.

Patient characteristics associated with self-management capacity

A large number of cross-sectional studies have evaluated the association between patient characteristics and varying self-management capacity to identify patients at risk for poor self-management capacity. Although not exhaustive a summary of the most important identified characteristics is provided below.

In the early nineties, Connely et al. already developed a conceptual model to increase the understanding of varying self-management capacity; the Model of Self-Care in Chronic Illness (MSSCI)⁷⁸. In chronic disease patients, gender, age, income, education, social support, symptom severity and comorbidities were initially identified as determinants of self-management capacity⁷⁸.

Table 1. Characteristics of tailored interventions in heart failure (HF) self-management trials.

Author, year	n	Intervention	Tailoring variables#	Customization variables			Theory underlying intervention		
				Content/themes	Mode of delivery	Dose/frequency			
Angermann et al. ⁷²	2012	715	Nurse-led telephone contact intervention during 6 months	Knowledge, needs, NYHA class.	X		X	NR	
Atienza et al. ¹⁰⁶	2004	338	Nurse-led intervention with 1 session prior to discharge, tele-monitoring, a visit with PCP and 3-monthly follow-up visits at cardiologist (during 1 year)	Knowledge of disease, ability to identify signs and symptoms of heart failure worsening, response to deterioration, patients' performance.	X			NR	
Barnason et al. ⁶⁷	2010	40	Nurse-led intervention with 1 face-to-face and 2 telephone contacts	Health literacy, medication adherence, medication perceived needs.	X		X	Social cognitive and learning theory and the medication adherence conceptual framework	
Clark et al. ⁶⁸	2014	50	Nurse-led intervention with 3 months of biweekly individual sessions followed by 3 months of TCs/emails	Interest of the participant.			X	X	Based on a conceptual model by Stuijbergen et al. (combination of health promotion theory and self-efficacy theory)

Table 1. continued

Author, year	n	Intervention	Tailoring variables#	Customization variables			Theory underlying intervention
				Content/ themes	Mode of delivery	Dose/ frequency	
Cockayne et al. ¹⁰⁷ 2014	260	Nurse-led intervention with 6 individual sessions	Cardiac misconceptions, discussion of patient's medication and of the patient's risk factors	X			Not described, but use of cognitive behavioral strategies
DeWalt et al. ⁷⁵ 2006	605	Health educator-led intervention with individual session and TC FU for 12 months	Patient's knowledge and interests.	X			NR
DeWalt et al. ⁶³ 2012	605	Health educator-led intervention with individual session and TC FU for 12 months	Patient's knowledge, behaviors and language preference.	X	X	X	The social cognitive theory and learning theory
Dickson et al. ⁶⁴ 2014	75	Lay health educator led intervention of twice-weekly, 1-hour group session for 4 weeks	Knowledge, skills, circumstances and needs.	X	X		The situation-specific theory
Dracup et al. ¹⁰⁸ 2014	602	Nurse-led intervention with 2 intervention arms of 1 individual session and per arm different frequencies of TC FU.	Medication list, barriers, content competency.	X			NR
Dunagan et al. ⁶⁹ 2005	151	Nurse-led telephone intervention with telephone contact and/or 1 home visit	Patients' clinical status and self-management abilities.			X	NR
Dunbar et al. ¹⁰⁹ 2013	170	Nurse-led intervention of 2 (group) sessions in 2 months and the second arm additional 2 sessions (+2 months).	Perceptions of living with HF. Sodium intake and medication adherence. Dyads autonomy support and family criticism scores.	X			Self-determination theory
Ekman et al. ⁷⁰ 1998	158	Nurse-led intervention with telephone and/or individual contacts up to 6 months	Understanding of disease and treatment, and relevant psychosocial and lifestyle factors.	X		X	NR
Jurgens et al. ¹¹⁰ 2013	99	Primary investigator (nurse)-led intervention of 2 individual sessions within 10 days.	Sensations of dyspnea and fatigue.	X			Theory of heart failure self-care
Leventhal et al. ¹¹¹ 2011	42	Nurse-led intervention with one individual session and FU with 17 TCs	Physical, psychosocial and environmental assessment.	X			Not clearly described but a component of the self-efficacy theory is included
Jaarsma et al. ¹¹² 1999	179	Nurse-led intervention with a TC 1 wk and a visit 10 days after discharge	Patients' needs and potential problems.	X			NR

Table 1. continued

Author, year	n	Intervention	Tailoring variables#	Customization variables			Theory underlying intervention
				Content/themes	Mode of delivery	Dose/frequency	
Otsu et al. ¹¹³ 2011	96	Nurse-led intervention of 6 individual sessions during 6 months	Sodium use, level of compliance and performance at home.	X			Theory of cognitive behavior
Riegel et al. ⁷¹ 2002	358	Nurse-led TC intervention up to 6 months after discharge	Symptoms, knowledge and needs.			X	NR
Riegel et al. ⁶⁵ 2004	88	Peer support intervention with weekly contacts for 3 months	Patient preferences and based on interaction mentor and mentee.	X	X	X	Social support model
Riegel et al. ⁶⁶ 2006	134	Nurse-led TC intervention (same as Riegel 2002 but now targeted to Hispanics)	Symptoms, knowledge, needs and language/ culture.	X	X	X	NR
Shao et al. ¹¹⁴ 2013	108	Research assistant led intervention with 1 individual visit and 4 TCs within 12 weeks	Self-management behaviors and problems.	X			Social cognitive and learning theory
Shearer et al. ¹¹⁵ 2007	87	Nurse-led intervention with 6 telephone calls within 12 weeks after discharge	Needs, goals and health concerns	X			Theory of Unitary Human Beings
Shively et al. ¹¹⁶ 2005	116	Nurse-led intervention of four group classes and 3 TC's in 4 months	Behavioral goals.	X			Information-behavior-motivation model
Shively et al. ⁷⁷ 2013	84	Nurse-led intervention of 6 individual face-to-face or TC sessions during 6 months	Activation level.	X			Patient activation theory
Sisk et al. ¹¹⁷ 2006	406	Nurse-led intervention with 1 visit and FU TCs for 12 months	Daily sodium intake, medication adherence.	X			NR
Wakefield et al. ¹¹⁸ 2008	148	Nurse-led intervention with 14 TCs or videophone contacts within 11 weeks.	Symptoms and skills.	X			NR
Wongpiriyayothar et al. ¹¹⁹ 2008	93	Researcher-led intervention with 2 home visits en 2 FU TCs within 12 weeks	CHF symptom management, barriers, cooking pattern	X			Conceptual framework of symptom management model developed by Dodd et al. and coaching strategies

[#]Variables used to assess patients and assign them to a tailored intervention component. NYHA: New York Heart association, PCP: primary care physician, TC: telephone contact/consultation, FU: Follow-up, NR: Not Reported.

The determinants hypothesized in the MSSCI have been tested in multiple HF populations with relatively inconsistent findings. Rockwell et al. found level of education and symptom severity to explain 10.3% of the variance in self-management capacity⁷⁹. A subsequent study could not replicate these findings, but found that males and patients with less comorbidities were more likely to be good self-managers³⁰. Partly similar findings were found by Cameron et al. where older age, male gender, comorbidities and depression were associated with poor self-management capacity³¹. The association with depression⁸⁰ and poor self-management capacity has been replicated in several studies^{32,81}. Besides depression, anxiety and cognitive dysfunction are highly prevalent in patients with HF and seem to complicate engagement in self-management^{32,82,83}. Performance in self-management also seems to be influenced by experience. Two studies have investigated the relation between the time from diagnosis and showed better scores for experienced patients on self-care maintenance and self-care management scores but surprisingly not on self-care confidence^{84,85}. Other important characteristics that have shown to hamper self-management behaviors in HF are both low literacy and low health literacy. For patients with inadequate literacy it is more difficult to understand health information and act upon it to perform good self-management⁸⁶. For low health literacy, several studies found it to be independently associated with poor self-management capacity⁸⁷⁻⁸⁹.

Alongside designating patients with a higher likelihood for poor self-management capacity, decision-making on tailored strategies might also be served by getting an in-depth understanding of varying self-management behaviors. Meanwhile two recent meta-syntheses have been conducted, synthesizing results from a large number of qualitative studies aimed at increasing our understanding on varying self-management capacity^{90,91}. The first included 23 studies and indicated that disease severity, limited knowledge, comorbidities, cognitive and emotional dysfunction, communication skills and adverse coping strategies were barriers for adequate self-management capacity. Facilitators were social support, disavowal (healthy denial) coping strategy, trust in health care providers, spiritual beliefs and optimism⁹⁰. The most recent meta-synthesis mainly focused on the impact of different contextual factors and included 45 studies. Strachan et al. identified six main types of contextual factors to complicate self-management in HF patients: lack and overload of caregiver support (usually family members), limited social networks, living in rural areas, limited financial capacity, and limited interaction with peers⁹¹.

Summarizing the great efforts that have been made, we can draw a tentative conclusion that age, gender, (health) literacy, socio-economic class, comorbidities, emotional and cognitive function are key recurring patient characteristics that are associated with self-management capacity. It is appealing to assume that results from cross-sectional studies might help us to guide targeting or tailoring interventions. Yet, factors associated with self-management capacity are not necessarily those with a higher likelihood for success of

self-management interventions. The cross-sectional nature of these studies only provide a snapshot of the association at one time point and give no indication of causal mechanism occurring over time initiated by an intervention.

Patient characteristics associated with success of a given intervention

In contrast to cross-sectional analyses which solely allow for the identification of characteristics associated with self-management capacity, decision making on tailoring can be facilitated by unraveling success of self-management interventions. Quantifying in whom a given intervention is most likely to be successful can be analyzed by identification of effect modification^{92,93}. Effect modification is defined as the difference in the association between the treatment and outcome across different subgroups of patients⁹⁴.

Effect modifiers can be identified by stratified analysis where the association between the intervention and outcome is reported for each level of a baseline characteristic. Differences in this association suggest the presence of effect modification⁹⁵. Another method is the measurement of statistical interaction, whereby the statistical significant contribution of the product term between treatment exposure and the baseline characteristic indicates effect modification⁹⁴. To identify patient characteristics modifying success of HF self-management interventions we could again rely on the selection of randomized trials as reported in the previous section.

Table 2 shows the results of studies evaluating effect modification including the type of analysis and included baseline variables. From the 52 interventions, twelve analyzed the presence of effect modification. The majority focused on demographic variables. None of the studies found differences in success of self-management interventions across different levels of age^{40,42,50,63,96} or race^{50,63,96}. This finding is in contrast to well established associations between these characteristics and self-management capacity. The same accounts for gender differences except for Mårtensson et al. who found subtle gender-specific differences in effectiveness of a nurse-led self-management intervention on SF-36 subscales in the advantage of women⁵⁶. In an additional analysis on self-management behaviors they showed this could have been mediated by women having a higher tendency to improve adherence to daily weight control⁹⁷. Two separate studies evaluated effect modification in the HART trial and evaluated the impact of low socio-economic class. Although not associated with change in HRQoL⁶³, low income patients (annual family income of <\$30.000) receiving a self-management intervention had 44% longer time to hospitalization or death compared to low income patients receiving education only⁵⁰. The same direction of association is seen for level of education. Although previous cross-sectional studies (incl. qualitative studies) have shown that low education is associated with

poor self-management capacity, additional analysis nested in a large Dutch trial⁵⁷ indicate that in fact this group might particularly benefit from the widely validated Chronic Disease Self-Management Program (CDSMP)⁹⁸. The authors found that patients attended <12 years of education gained more improvements in HRQoL compared to their higher educated counterparts. In the same study, cognitive function was identified as an effect modifier of success of CDSMP too, favoring those with a higher baseline cognitive status⁹⁸. The impact of low literacy on success of self-management interventions has been thoroughly investigated by DeWalt and colleagues. Initially, in a relatively small single center RCT, this research group evaluated the effectiveness of a literacy-sensitive intervention. Although statistically underpowered, they performed a stratified analysis within two levels of baseline literacy and found no indications for effect modification⁷⁵. In a subsequent larger trial (n=605) they examined the difference in effectiveness between a single session self-management intervention and additional telephonic reinforcement. They reported the impact of age, sex, education, income, ethnicity, NYHA class and literacy and change in several outcome measures. Only literacy was identified as an effect modifier of the extensive intervention. While emphasized in many studies as a factor hindering successful self-management behavior, having a baseline low/marginal literacy was associated with a higher likelihood for success both in HRQoL⁹⁹ and number of hospitalizations⁶³.

Five studies^{40,50,57,63,96} evaluated effectiveness of the self-management intervention within strata of HF-specific characteristics such as severity (NYHA class, ejection fraction, time from diagnosis) and ischemic etiology. Only Bocchi et al. found that in patients with baseline NYHA I-II a program with repetitive education and telephone monitoring resulted in a larger risk reduction on the composite outcome hospitalization or death⁴².

Table 2. Effect modification in longitudinal HF self-management studies.

Author, Year	Contrast	Effect modification analyses	Baseline variables analyzed for effect modification	Outcome	Effect modifiers identified
Aldamiz et al. ⁴⁰ 2007	SM vs usual care	stratified analysis	age, sex, etiology, ejection fraction, original admission due to non-adherence	combined outcome death/hospitalizations	admission due to non-adherence = ↓ events low / marginal literacy = ↑ gain in HRQoL
Baker et al. 2011 & DeWalt et al. 2012 ^{63,99}	SM vs usual care SM vs multiple sessions vs SM single session	stratified analysis / interaction analysis	age, sex, education, income, race, NYHA class, literacy	self-efficacy knowledge self-care behaviors hospital admissions	NONE NONE NONE
Bocchi et al. ⁴² 2008	SM vs usual care	stratified analysis	age, sex, NYHA class, ethnicity, DM, etiology	combined outcome death/hospitalizations	low / marginal literacy = ↓ events NYHA I/II ⇒ ↓ events
DeWalt et al. ⁷⁵ 2006	SM vs usual care	stratified analysis	literacy	HRQoL combined outcome death/hospitalizations	NONE NONE
Heisler et al. ⁴⁶ 2013	SM vs usual care	stratified analysis	sex	TTE combined outcome death/hospitalizations	NONE
Jaarsma et al. ¹⁰⁰ 2010	SM vs usual care	interaction analysis	depression	combined outcome death/hospitalizations TTE death hospitalizations TTE hospitalizations	depression = ↑ events depression = ↓ time to event depression = ↑ events depression = ↓ time to event depression = ↑ events
Laramee et al. ⁴⁸ 2003	SM vs usual care	stratified analysis	distance from hospital, care from local specialist	hospital admissions	shorter distance from hospital = ↓ events care from local specialist = ↓ events
Martensson et al. ⁵⁶ 2005	SM vs usual care	stratified analysis	sex	generic QoL	female = ↑ generic QoL
Powell et al. 2010 & Grady et al. 2014 ^{50,96}	SM vs enhanced education	interaction analysis	age, sex, education, income, race, 6MWT, comorbidities, systolic function, drug adherence age, sex, race, education, income, depression, NYHA class	combined outcome death/hospitalizations TTE death/hospitalization HRQoL	NONE low income (< \$30,000/y) = ↓ time to event NONE
Shively et al. ⁷⁷ 2013	SM vs usual care	interaction analysis	PAM	hospital admissions, ED visits PAM	low or High PAM scores = ↓ events NONE medium PAM scores = ↑ gain in PAM
Smeulders et al. ⁹⁸ 2010	SM vs usual care	interaction analysis	age, sex, time from diagnosis, NYHA class, comorbidities, education, living status, cognition, employment	HRQoL	higher cognitive function = ↑ gain in HRQoL lower education = ↑ gain in HRQoL

HRQoL: Health Related Quality of Life, PAM: Patient Activation Measure, ED: Emergency Department, 6MWT: 6 minute walking test, NYHA: New York Heart Association, TTE: Time To Event, DM: Diabetes Mellitus

As a reflection of disease complexity, two studies have evaluated the impact of comorbidities. Although operationalization of comorbidities varied, no indications for effect modification were observed^{50,57}. Yet, specific comorbidities do seem to hinder the success of self-management. In addition to the negative influence of low cognitive function, as indicated earlier, baseline depression might also lead to less successful outcomes of self-management interventions. Whilst no effect modification was identified for HRQoL in the HART trial⁹⁶, interaction analysis in the COACH trial showed that the intervention was only effective on time to death/readmission and reduced mortality rates in patients without depression¹⁰⁰.

Few studies have analyzed whether baseline self-management competences can influence success of interventions. One might assume that the initial level of HF-specific self-management behaviors and known mediators of change in self-management capacity such as self-efficacy and activation determine the didactic room for improvement. This is supported by the interaction analysis nested in a Spanish RCT where they analyzed a broad range of potential effect modifiers. In a subgroup of patients whose original admission was attributed to non-adherence, the risk reduction for combined readmission or death rate was significantly greater⁴⁰. Shively et al. studied the impact of baseline levels of activation, as measure by the PAM on success of a self-management intervention⁷⁷. Their results indicated that moderately activated patients were the ones with the highest likelihood for a positive change in the PAM, while in low and highly activated patients the intervention resulted in a higher reduction in hospitalizations. Interpretation of these results is complicated by the fact that the intervention was tailored based on patients' initial level of activation⁷⁷.

In summary, age, ethnicity, gender, number of comorbidities and disease severity do not seem to influence the success of self-management interventions. Low education, low income, low literacy and low baseline self-management capacity seem to facilitate success, while depression and cognitive dysfunction seem to hinder success of self-management interventions.

Clinical implications

To curb the complexity of HF and to reduce its impact on patients and society a multi-faceted approach is needed, in which patients have an important responsibility in determining the course of their disease. Improved self-management capacity contributes to better HF-related outcomes and reduction in hospitalizations and mortality. Interventions aimed at supporting patients in increasing these competences have shown to be successful, however, not in all patients. To optimize effectiveness of those interventions prompts the use of better targeted or tailored interventions. It is likely that adaptive interventions,

combining the identification of certain subgroups and subsequent tailored solutions will result in higher effect sizes. However, within the large number of available trials, the degree to which interventions are explicitly tailored is marginal.

For future interventions and to support clinical practice we have summarized the results of many scientific efforts to identify patient characteristics that are clinically relevant to guide targeting and tailoring. For age, gender, ethnicity, disease severity and number of comorbidities, substantial evidence is available that these factors do not seem to influence the degree of success of self-management interventions. Other characteristics initially identified as factors potentially hindering effective self-management in longitudinal studies are in fact indicators of those patients with the highest likelihood for improvement. Knowledge of these effect modifiers gives rise to formally include these factors in the screening process, especially when more efficient allocation of resources is indicated. Patients with low literacy, low education and low income at baseline have shown to be suitable candidates for self-management support. It can be expected that more tailored approaches can even further boost effect sizes (e.g. (health) literacy sensitive interventions). Effective guidelines are available to provide patients with additional support, adapt communication strategies and educational content and materials^{86,101}. Low income patients already seem to benefit from current self-management interventions, yet policy-makers should stay vigilant to prevent financial factors from hindering the effects of self-management.

Another important aspect is the baseline assessment of self-management capacity including important mediators of behavior change such as self-efficacy, knowledge, adherence and activation. A limited number of studies indicate that initial poor self-management behaviors do not hinder but instead represent those with a high didactic potential for improvement.

Current evidence of effect modification in clinical trials indicates that certain characteristics do hamper the likelihood for success of self-management interventions. Cognitive dysfunction and depression are highly prevalent comorbidities in HF and both seem to have negative impact on the effectiveness of self-management interventions. Therefore, formal screening at baseline for these factors is imperative. For cognitive dysfunction, both learning and subsequently performing self-management is highly challenging. In current available trials, interventions seldom formally screen for cognition and do not seem to be sensitive in sufficiently tackling the influence of cognition on increasing self-management competences. It seems sensible that interventions in this subgroup of patients need to be extended with increased assistance, allocation of caregivers, cognitive training and environmental manipulations, i.e. by simplifying tasks, providing external cues or prompts to initiate action⁷⁴. Given the high prevalence in the HF population, the impact of depression on success of self-management is disturbing. Although little evidence is available on tailored strategies in this subgroup, it seems useful to incorporate screening

of depressive symptoms at enrollment and to consider cognitive behavioral therapy or to add antidepressants¹⁰².

Research implications

Extensive scientific work has been done to increase our understanding in whom self-management is problematic and in whom self-management interventions are most effective. Yet, the interplay between patient characteristics, self-management capacity and the likelihood for success of interventions is still unclear. In our quest to establish tailored HF self-management we should slowly abandon from cross-sectional analyses, since many studies already have been performed and they have provided limited information on the causal mechanisms towards success. Instead, decision making on tailored strategies is served by comprehensive identification of effect modifiers from longitudinal studies.

Understanding the variance in effectiveness among subgroups is complicated by the heterogeneity in available intervention strategies. Substantial variations in intervention components, mode of delivery and dose hamper answering ‘what works in whom’; the key towards effective tailoring of future interventions. Increased scientific efforts are needed to validate the modifying impact of currently known characteristics such as (health) literacy, education, income, cognitive and emotional status across different treatment strategies. In addition, more knowledge is needed on the extent to which initial self-management capacity and levels of key baseline behavioral mediators reflect the potential for improvement. Stratified analysis in well powered randomized trials, preferably with multiple treatment arms can help us to further unravel the causal mechanism between patient- and intervention characteristics. Additionally, data from longitudinal routine-care cohorts and an ongoing Individual Patient Data meta-analysis³⁵ can help us to untangle success of self-management as a bridge towards more individually tailored strategies.

Available trials on HF self-management have not always clearly described how tailoring was applied. The minority of studies which explicitly described the tailoring strategy generally limited tailoring to individualizing content. Guided by the accumulating knowledge in this field, future studies are needed to study the added value of tailoring interventions in terms of behavioral change techniques¹⁰³, mode of delivery (i.e. regular consultations vs. e-Health solutions) and intensity. A promising design to this purpose is the use of adaptive interventions designs, whereby the type or dosage of the intervention is adapted based on patient characteristics and the treatment is adjusted repeatedly over time¹⁰⁴. These interventions use individual differences between participants to achieve the best possible outcome, both by augmenting an intervention for a non-responsive participant or diminishing treatment for a responsive participant in order to reduce cost or participant burden. Sequential, multiple assignments, randomized trials (SMART) can be used to test the decision rules for an adaptive intervention¹⁰⁵.

Conclusion

Although embedded in HF guidelines, effectiveness of self-management interventions has not yet reached its full potential. Effectiveness can be substantially optimized when interventions are better tailored to individual patients. Currently available trials did individualize the intervention to a certain extent, however this was rarely applied through explicit identification of certain subgroups and subsequent provision of tailored solutions. In this review we synthesized essential literature which can serve as building blocks for future development of tailored self-management approaches. The results show that we have to redirect our efforts: several characteristics previously considered to be associated with poor self-management capacity (age, gender, ethnicity, disease severity, number of comorbidities) actually do not affect effectiveness of a given intervention. Other factors such as low income, low literacy, low educational level and low baseline self-management capacity in fact point at those patients with the largest potential for improvement. Identifying those patients with a high likelihood for success can increase effectiveness of interventions. Particular emphasis should be placed on pro-active screening and attempts to develop and validate tailored strategies for patients with cognitive or emotional dysfunction. Meanwhile scientific efforts are needed to unravel success of self-management interventions and the added value of tailoring.

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4

Nurses' assessment of patients' potential for self-management in chronic care

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Abstract

Background: Although self-management interventions are to some extent individualized in clinical practice, we do not yet fully understand the decision-making process. Exploring nurses' clinical reasoning in how and to what extent they currently tailor self-management support can provide new insights enhancing process and outcome of chronic care.

Objectives: To explore how nurses assess chronic patients concerning the potential of self-management and clinical reasoning with regards to tailoring care to the individual patient.

Method: A qualitative study was conducted using grounded theory. Semi-structured interviews were held with 15 nurses working within chronic care. All interviews were carried out from February to July 2013

Results: All nurses provided individualized care; however, the nurses' view of self-management influenced how tailoring is performed. Substantial differences were seen in patient assessments and in how care was individualized. Patients' motivation, capacities, mindset, needs and preferences were obtained through communication, experience, intuition, and trusting relationships. Four patient typologies emerged from the data: the unmotivated patient, the patient with limited capacities, the oblivious patient and the ideal patient. Nurses elaborated on using different approaches for each of these patient subgroups.

Discussion: Nurses' perception of self-management substantially impacted how care was individualized. Patient assessment was the key driver of tailoring, which was performed in various ways and influenced how and the extent to which care was individualized. To enable responding to the unique wishes and needs of individual patients both scientific and educational efforts need to be directed towards systematic assessments of patients' capacity to self-manage their disease.

Introduction

Worldwide, the amount of patients with a chronic disease is expanding rapidly, and future projections show that this increase will intensify in the coming years, accompanying higher costs and laying a burden on the health care system ^{1,2}. Self-management support is seen as a promising way to meet the needs of patients suffering from chronic diseases and to decrease the burden that chronic disease puts on the health care system. Self-management is a mature concept in chronic illness literature, yet its meanings and definitions vary greatly ³. Self-management was defined by Barlow and colleagues as: "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life" ⁴.

Despite the high expectations, several meta-analyses have shown that the success of self-management support varies between individuals ^{5,6}. Face-to-face delivery of personalized health messages has proven to be a feasible and effective method of creating behavior change in patients ⁷. Tailoring self-management to the specific needs of a patient is expected to improve self-management efficacy ⁸. For personalized self-management, health care providers should be able to identify patients' psychosocial characteristics and needs ⁷.

During the past few decades, management of some of the most prevalent chronic conditions (diabetes mellitus and COPD) in the Netherlands has shifted from secondary to primary care, and tasks have been reallocated from physicians to nurses ⁹. For more complex chronic conditions, care is still largely provided by specialists and specialized nurses ⁹. Because nurses currently play a prominent role in chronic care, they are important in providing self-management support ¹⁰. Little is known about how and to what extent tailored self-management is provided in daily practice and whether and how patients are assessed regarding their eligibility for self-management support.

During their consultation, nurses gain an impression of patients, which helps them determine whether patients are interested in and suitable for self-management. A previous qualitative study concluded that nurses' first impressions appeared to determine expectations of self-management abilities in long-term conditions. This study did not thoroughly explore how the assessment occurred and did not report how this assessment ultimately influenced the nurses' decisions concerning self-management approaches ¹¹. Lake et al. reported that clinicians make subjective assessments of patients' individual needs. Based upon these assessments, combined with experience and the available self-management techniques (in their workplace), they make decisions on the most appropriate approach for the patient ¹². Additional studies have investigated possible barriers and facilitators for self-management (e.g physical limitations, lack of knowledge, financial resources, co-morbidities, illness

perception, personal struggles, social support), and the results suggest that assessment of barriers is imperative for individualized care ¹³⁻¹⁷.

Current evidence indicates large heterogeneity in treatment effects of self-management in patients with different chronic diseases. Tailoring self-management to the individual needs and preferences seems a good way to improve the effectiveness of self-management interventions, although little is understood of how this should be incorporated in daily practice. Therefore, this study explored the clinical reasoning of nurses providing care to chronic patients regarding self-management. More specific, the study explored how and to what extent nurses currently individualize self-management support, which can provide new insights enhancing self-management support and outcome of chronic care.

Methods

Objective

The main aim of this study is to explore how nurses assess chronic patients concerning their potential for self-management and clinical reasoning with regards to tailoring chronic care to the individual patient. To explore this main aim four research questions were addressed with the following aims:

1. Identifying the perceptions of nurses on self-management.
2. Identifying factors that might influence the success of self-management.
3. Understanding how nurses assess chronic patients regarding the potential of self-management.
4. Understanding how nurses tailor their care regarding self-management.

Design

A qualitative study, using grounded theory, was conducted to describe how nurses individualize self-management support. The study draws on the method of constructing theory on meanings and actions as described by Charmaz ¹⁸ and resulted in a theoretical model that represents the nurses' assessment and strategies in supporting self-management in chronically ill patients. To facilitate the analysis of data that represent a multifaceted complex situation the Qualitative Analysis Guide of Leuven (QUAGOL) was used ¹⁹. The QUAGOL is a comprehensive method to guide the qualitative analysis in grounded theory.

Participants and sampling

Participants were nurses specialized in providing chronic care to patients with a chronic condition. Nurses were identified through the Dutch Nurses Association. It was hypothesized that variation in age, work setting, years of experience of nurses and variation in patient population would provide a good starting point for initial sampling. All identified nurses filled out a short questionnaire in advance to facilitate purposeful selection. Three nurses

in secondary care were directly asked to participate.

Data collection and data analysis alternated. Initially, a purposive sample of five nurses with a variation in characteristics was selected. Subsequently, theoretical sampling was used, aimed at respondents who could contribute to the evolving theory¹⁸. On reaching saturated categories three more primary care nurses were recruited working with a diversity of chronic conditions to refine the categories and test the model. Finally, two nurses, who were experienced, specialized in one chronic disease and working in secondary care were included, since we expected them to be more experienced in self-management support and aimed to deepen and validate the self-management strategies.

Data collection

Data were collected through semi-structured face-to-face interviews. A topic list, based on literature review and expert knowledge, was created to serve as a flexible framework for questioning. The topic list covered the four aims presented above (see Additional file), and was adjusted according to new insights during the analysis phase. Interviews were conducted by two researchers (IB and ED); both were present at 11 of the interviews. The interviews lasted 55 minutes on average (ranging from 33 to 88 minutes). Interviews were tape-recorded and transcribed verbatim. All interviews were conducted in Dutch and quotes were translated by IB and ED and subsequently checked by a bilingual native English speaker. Data collection through theoretical sampling was continued until saturation was reached

Ethical considerations

Nurses were asked to participate on a voluntary basis. They were asked to fill out an informed consent form that stated that interviews were recorded, that their anonymity was guaranteed and that they could withdraw from the study at any time. Since no patients were involved and nurses are only asked to give their perspectives, this research did not fall under the Dutch Medical Research Involving Human Subjects Act (WMO) or the Embryos Act, so that no ethical permission was required.

Data analysis

As a first step, the QUAGOL lead us into re-reading the interviews to familiarize ourselves with the data and in making narrative interview reports and come to conceptual interview schemes. By using constant comparison we were able to draw up a list of concepts for coding. Furthermore, for the development of the code tree, the first three interviews were read and meaningful fragments (incidents) were coded by three researchers (IB, ED, MK). Differences were discussed until consensus was reached. We coded the data as actions to create a theory that corresponded to the contributions of our participants¹⁸. New data were continuously examined using constant comparative methods, leading to adjustments

of the code tree, developing and filling categories and identifying relationships between categories. The steps of the QUAGOL are in line with initial, focused, axial and theoretical coding as described in the guidebook of Charmaz. Furthermore, an overview was made of our relevant findings to identify relationships between categories and to construct theory. The software program NVivo Version 10 was used to help us process our coding system ²⁰.

Rigor and reflexivity

The QUAGOL introduces rigor by safeguarding essential principles of qualitative analysis and using a team approach. Three researchers (IB, ED and MK) were involved during the entire process from data analysis through theory generation. Researcher triangulation was thus achieved and rich due to the variation in backgrounds (medical, health science and nursing). Furthermore, a broader research team, with expertise in the before mentioned fields, was involved in the design of the study, the development of the interview guide and thought along in the data analysis.

Results

Participant characteristics

Fifteen female nurses were interviewed. In line with theoretical sampling strategies we identified nurses with a variation of characteristics. Since the majority of nurses worked in primary care, the patient populations were mainly diabetes, respiratory and cardiovascular risk patients, complemented with secondary care nurses working with respiratory, diabetes, heart failure and rheumatic patients. Demographic and background characteristics of the participants are summarized in Table 1.

Table 1. Participant characteristics

Participant characteristics	N (=15)	%
Age (range 28-59)		
≤35 years	3	20
>35≤45 years	2	13.3
>45≤55 years	5	33.3
>55 years	5	33.3
Years of experience (range 2-20)		
≤5 years	4	26.7
>5≤10 years	4	26.7
>10≤15 years	4	26.7
>15 years	3	20
Patient population		
Diabetes mellitus	9	45
COPD/asthma	9	45
Other	2	10
Location		
General Practice	10	66.6
Hospital	3	20
Both	2	13.4
Consultation time		
30 minutes	11	73.3
15-20 minutes	4	26.7

Nurses' perceptions of self-management

All participating nurses were familiar with self-management and stated that they performed self-management support to a certain extent. For some nurses, it was a common practice, whereas others had recently started to implement self-management in daily practice. In asking about definitions for or associations with self-management, different perceptions of self-management were observed. Several nurses indicated that self-management is a

broad and rather complex concept.

Well, what is self-management? It is quite broad... nutrition, exercise, pill intake, taking good care of oneself. That's all part of self-management, no matter how. (N3)

The responsibility shift from provider to patient was frequently mentioned. Furthermore, patients were seen as central in and responsible for their disease care. This finding implies that patients should learn to cope with their disease in their own way and make informed choices. For some nurses, responsibility for the disease meant that the patient, instead of the caregiver, should take initiative to engage in self-management tasks. Other nurses emphasized the importance of facilitating self-management in each individual patient.

Nurses mentioned various reasons to facilitate self-management. Many aimed to achieve health gain, increase quality of life and enhance patients' responsibility in caring for their disease. For some nurses, self-management was an aim itself. However, not all nurses could mention clear aims for providing self-management support.

Nurses said that they considered their role to be crucial in facilitating self-management support. They regarded informing patients and creating awareness about their influence on the course of their disease as the nurse's responsibility. However, nurses mentioned that time constraints hindered their care and therefore needed to efficiently use their time. Furthermore, nurses indicated that self-management should be a shared responsibility of an entire health care service to accomplish its full potential.

The general setting remains very much like 'your wish is our command'. I think that if you really want to implement self-management in general practice, everyone involved has to work in unison, and that means setting the bar high. (N6)

Regarding the proportion of patients with self-management potential, the nurses had different opinions. Some nurses indicated that the vast majority of patients do not succeed in self-management. Others claimed that only a minority of patients does not succeed and that self-management is effective in most patients, although sometimes only small steps can be taken.

Assessment of self-management potential

Nurses had difficulties explaining how the assessment specifically occurred.

"Because there are a lot of things you do without thinking about it. It is hard to put into words what it is exactly that you do, you know." (N1)

Both verbal and nonverbal communication were said to be important. Several nurses indicated that they used structured ways, either by history taking or using a questionnaire that screened all relevant aspects. There were substantial differences in the ways in

which nurses assessed chronic patients and the extensiveness of these assessments. They mentioned that they used their intuition, experience and (tacit) knowledge. Most nurses assessed whether a patient would become a 'good' or 'bad' self-manager. Nurses also mentioned that they needed to be aware of prejudices because time would be the best indicator of how a patient would respond to self-management.

Most nurses had previously undergone a motivational interviewing training, which was highly valued by all. In addition to increasing patients' motivation and awareness, nurses reported that motivational interviewing assisted them in discovering how self-management can be tailored to the individual patient.

"Motivational interviewing is a must for everyone who deals with patients. [...] That'll bring out a lot. And then you'll see clearly how people become aware themselves at some point, without having to make them aware. By the way of your questioning. Yes, they'll figure it out themselves. I think that's the best way, because as a nurse, you can say all you want, like 'yeah, you should stop smoking', but that's not going to work of course." (N9)

Obtaining a clear picture

Many nurses indicated that gaining insight into patients and how they experience their disease was important to better understand the patients' perspective. Generally, this insight takes time and involves subsequent consultations to determine how patients progress and improve. Gaining more information helped them to understand what difficulties patients face and where they needed assisted decision-making to improve.

I just like to know more about people. It's totally fine by me that people will tell their life stories because that may come in handy later to get people to become enthusiastic to do certain things. (N2)

They use this information to motivate patients to take certain actions. Furthermore, this process created opportunities to respect and respond to the unique wishes and needs of patients. However, several nurses stated that they attached less importance to thoroughly gaining a clear picture of patients' everyday lives and backgrounds, sometimes because of time constraints.

A few nurses mentioned that building a strong relationship and mutual trust helped to gain a good impression because the patient was more comfortable with sharing personal information. Additionally, nurses indicated that patients with involved and compassionate nurses would more readily improve their self-management.

In the beginning, especially with self-management, building confidence amongst each other will be very important. People need to feel safe in order to feel comfortable talking

about themselves. Because once someone holds back [information], well, naturally, then it will get harder to help too. (N10)

Factors influencing success of self-management

Nurses mentioned multiple factors that were barriers or facilitators for the success of self-management. They indicated that they should be aware of their own prejudices and were hesitant to generalize. A barrier to one patient may not be a barrier to another. They reported the following factors for assessment: motivation; knowledge and understanding of the disease; coping skills; passive or dependent attitude; self-efficacy; socio-economic status (SES); literacy; cultural differences; health condition; educational level; financial circumstances; psychiatric disorders; cognitive impairment; age; and presence of a support network. However, the most mentioned factors that made patients less suitable for self-management or in which nurses encountered difficulties in performing self-management were patients with a lack of motivation or with less capacities to fulfill self-management and/or were oblivious to self-management.

Four patient typologies

From the nurses' responses, we identified three types of patients in which they encounter difficulties in facilitating self-management or they find less suitable for self-management: 'unmotivated patients', 'patients with limited capacity for self-management' and 'oblivious patients'. Furthermore, nurses recognized the 'ideal patient'.

'Unmotivated patients' were described as not being prepared to take an active role in the care process and unwilling to adhere to certain therapies, diets or other lifestyle changes.

There is just a group that is less motivated (N14)

When someone refuses help, he doesn't see the importance of certain medication and of lifestyle change advice, he just does not want to change it. (N15)

Nurses characterized these patients as having a closed posture, making excuses, wanting to end the consultation as quickly as possible and unaffected by the nurses' statements.

'Patients with limited capacity' were those in whom the nurses detected a lack of capacity to perform self-management tasks. Patients with little understanding of their disease were considered to have a low self-management potential.

Self-management actually requires a great deal of insight on many topics, and I wonder whether this insight is always present. (N10)

Additional barriers were a lower SES, cultural differences and lack of social support. In most

cases, barriers could be overcome or self-management could be adjusted to the individual patient. Finally, patients with psychiatric disorders or cognitive impairments were said to have serious restrictions to perform self-management.

...true incompetence, well, (mental) retardation or illness, or addiction to alcohol, or well anything, you name it. But, in that case, there will always be [professional] support.
(N12)

'Oblivious patients'. Nurses described a substantial amount of patients who were not aware of the suggested responsibility shift in the delivery of care. They were not familiar with adopting responsibilities for their own health and generally had a passive attitude. Nurses explained that the elderly and immigrants often lacked the knowledge on how to execute self-management tasks and expected their care to be delivered by the nurse instead of actively participating themselves.

That's how people keep coming to see you or the doctor. They will say 'I have diabetes, I should deal with that, now tell me what to do'. Well, that's how they put the problem in my lap, because then, when they happen to fail, it will be my fault! (N10)

'Ideal patients'. Nurses explained that these patients had a pro-active mindset, were intrinsically motivated to take action and had the capacity to perform self-management tasks. They had the desire to be informed and pro-actively searched for information. In addition, they were confident, not afraid to ask for help and rarely required guidance. All of the nurses were acquainted with patients who they assumed to be 'perfect self-managers'; however, this group represented a small proportion of patients.

Someone who understands his own disease and who really knows what the symptoms are. And who understands what his own role is and who is willing to play an active part. (N15)

Individualized self-management approaches

Figure 1 is an illustration of the individualization process globally described by the nurses and is explained in the text below. Most nurses determined whether patients were motivated, had the capacities and/or were oblivious to self-management. Sometimes, nurses encountered resistance towards self-management, and the reason for this resistance was not immediately clear (lack of motivation, lack of capacity or being oblivious). To clarify this resistance, we explored each reason as separate entities below. In addition to the tailored approaches within the various typologies, nurses elaborated on their general approach in facilitating self-management.

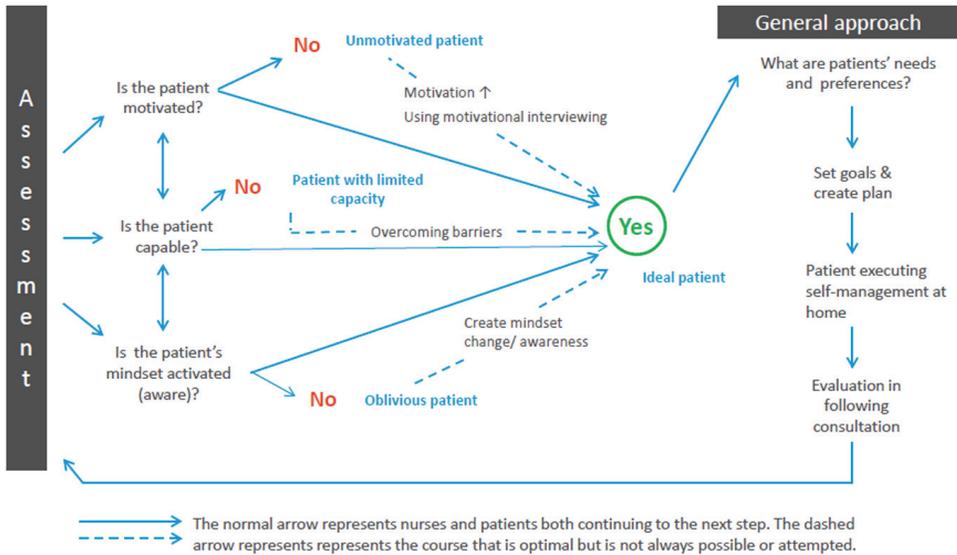


Figure 1. Model on how nurses assess chronic patients concerning the potential of self-management and subsequently tailor care to individual patients

General approach

In the case nurses thought there was potential for self-management, they explored the patient’s needs and attempted to determine the patient’s preferences in terms of self-management approaches. Accordingly, nurses and patients jointly established feasible goals and created a plan in which patients’ wishes prevailed. Most of the time, the nurse concluded the consultation by discussing the plan that was created, which was mostly likely not written down on paper for the patient to take home. If patients faced difficulties with performing self-management at home, they often could contact the nurse for further support. During subsequent consultations, nurses evaluated how patients had performed, repeated the assessment and, if necessary, reinforced or adapted goals and plans. Assessing patients and tailoring self-management was an implicit and discretionary clinical judgment process that continued throughout each consultation. Although the model in Figure 1 delineates the ideal situation, it should not be seen as a linear process. Nurses also attempted to establish goals and created a plan with patients who were not completely motivated or capable or who were oblivious.

Dealing with “unmotivated patients”

In facing a less-motivated patient, nurses applied motivational interviewing techniques to try to enhance patient motivation. A few nurses stated that they attempted to discover the underlying cause of the patient’s lack of motivation to address their reluctance, whereas others did not appear to give much attention to this factor. All of the nurses said that they

should not be aggressive and instead be reserved in confronting unwilling patients, and they felt that this approach was sometimes more effective in the long term.

I think that, especially at first, you begin to determine how far along someone is and if you notice a certain resistance or if you get the sense that someone is not quite ready for life style changes, then, I feel, you should back off. Because it [change] does have to come from within. (N1)

However, some nurses said that confronting patients with the consequences and risks of non-compliance and emphasizing their own responsibilities were effective. In reflecting on strongly reluctant patients, almost all nurses stated that at some point, they needed to respect the patients' choice and let go of certain self-management goals.

Some people really don't want anything. And if you've constantly tried, for real, to explain what the disease is about, so really tried to give them understanding about their disease [...] consult after consult you've tried, then you should just leave it and not continue flogging a dead horse. (N5)

Adapting (care) to "patients with limited capacity"

In patients with low self-management skills, nurses expressed that they needed to play a more leading role in setting goals and creating plans but always in agreement with patients.

So, basically I will try to engage them, but when I get the feeling it becomes too hard, then I will try and move into the driver's seat. And naturally, all by mutual agreement.

Nurses highlighted the importance of informing patients at their own level of understanding and adapting to their way of communication. Additionally, they adjusted self-management tasks according to abilities and financial restrictions. Furthermore, they gave patients time to grasp concepts at their own pace.

Sometimes I say 'take your time to think about it and schedule a follow-up appointment. We will continue our conversation. Sometimes people need a little time to grow used to the idea. (N4)

Nurses tried to discover what was possible within the restrictions of a specific patient and indicated that they needed to keep the process simple and be pleased with small successes. In some patients, self-management was not possible because of serious limitations, and self-management could not be pursued.

Raising awareness in “oblivious patients”

Nurses explained that in oblivious patients, a mindset change was essential for these patients to adopt more responsibilities. By informing patients, they increased awareness of the disadvantages of being dependent on the health provider because everyone is responsible for his/her own health.

Well, you will have to explain to a patient with a chronic disease to expect certain changes in their attitude towards life. Someone can only grab the bull by the horn if he knows what it [the disease] is all about and what the consequences will be. And that a person has a choice of whether to take or leave any advice about life or medication. You know, that they will have to keep returning to the hospital or GP. That one visit won't be enough. And that not only the medical professional but also the patient himself has a say in this [the treatment process]. Some [patients] will be easier to convince than others.
(N15)

Encouraging “ideal patients”

Ideal patients suggested topics themselves and were already self-managing. They only needed occasional encouragement and rarely required guidance. Therefore, they needed less frequent consultations. Nurses greatly enjoyed this type of patient because this manner of care delivery was what they strived for in all of their patients.

“Especially to those people who handle it well I would say ‘why don't you come once a year for the comprehensive blood sugar check-up and evaluation because you're quite capable of doing it yourself.’ (N3)

Boundaries of assessment and its effect on self-management support

The nurses' degree of effort to achieve self-management differed greatly. This difference is represented by the dashed lines in figure 1. All nurses did not distinguish these patient typologies nor did they assess them. Nurses who could distinguish these subgroups felt challenged to eliminate barriers, to discover the underlying reason that made a patient resistant and enjoyed trying to increase motivation or capacities and create a mindset change. However, other nurses more easily reverted to performing standard consultations following the paternalistic model, that places patients in the role of passive recipient ⁴, and ceased their attempts to accomplish self-management.

Discussion

This study explored how nurses assess chronic patients concerning their self-management potential and how they tailor care to the individual patient. We found that assessments were performed in various ways, from purely intuitive to very extensive assessments. This process has consequences on how care is subsequently tailored to the individual patient. Tailoring care to the individual patient is mostly conducted by jointly setting goals and creating a plan. However, in meeting patients who had difficulties in performing self-management support (namely “unmotivated patients”, “patients with limited capacities” and “oblivious patients”), nurses adopted various individualized strategies to increase motivation, overcome barriers or create a mindset change, whereas other nurses reverted to being a professional expert and abandoning self-management support.

Concept of self-management

The variation in definitions of self-management in the literature is reflected in the differing perceptions of nurses that appear to influence how nurses view their role in tailoring self-management. Some nurses aim to have the patient be in charge and take responsibility, whereas others focus more on lifestyle changes and equipping patients with skills to enable effective management of their disease. For many nurses, self-management has become an aim itself, whereas self-management should serve as a therapeutic tool to facilitate a higher purpose²¹.

Nurses' role in self-management

Nurses also reflected on their pivotal role in self-management; however, they recognized the importance of a working environment in which self-management is the shared responsibility of the entire health care service. This finding was also found in another study that reported that “not all providers work in settings that include an integrated approach to chronic care and support or advocate self-management”²².

Nurses' assessment of patients

Nurses had difficulty explaining how they assessed their patients and how they subsequently individualized their care. With regard to tailoring self-management, their clinical judgment and decision-making varied based on their intuition, experience and (tacit) knowledge. This implicit way of assessing patients was also mentioned by Lake et al.¹². Assessments were performed in various ways, ranging from implicit ways to extensive questionnaires. If the assessment was more intentional, the nurse was better able to tailor self-management to the individual patient. Novak et al. stated that “individual assessment is a critical first step to ensure that self-management support efforts address patient concerns in a meaningful way and support individual health behaviors necessary to manage the illness”²³.

In contrast to McDonald ¹¹, nurses did not base their judgments on first impressions but gained an impression of whether a patient would become a successful self-manager based on a process of repeated evaluations. Nurses mentioned that they wanted to get to know their patients well and that they had to build mutual trust. Consistent with our findings, Tarlier ²⁴ described the importance of ‘responsive relationships’, which are based on respect, trust and mutuality. As described by Kralik, “health workers need an understanding, non-judgmental approach to build care on a relationship that recognizes and values the person’s experience and perspectives”²⁵.

Barriers and facilitators leading to the patient typologies

Despite mentioning many barriers, nurses explicitly mentioned encountering difficulties in performing self-management support in patients who were “unmotivated”, “had limited capacities” or were “oblivious”. In contrast to these patient typologies, they mentioned the “ideal patient” in whom they do not find these barriers. In the literature, motivation and willingness are mentioned as important for self-management and behavior change ^{26,27}, and many barriers are described that lead to less motivation, limited capacities and being oblivious ^{13,15-17,23}.

In this study, some nurses only distinguished two subgroups; patients with or without potential for self-management. They considered all of the patients without potential for self-management as one group having difficulty adopting self-management. This perspective results in nurses not knowing ‘which buttons to push’ to enhance self-management capacities, although barriers could be influenced and overcome. The importance of addressing these barriers has been extensively addressed in the literature ^{16,28,29}. In addition to realizing that patients have to cope with their disease within their own environment on a daily basis, health care providers need to understand and incorporate social, economic, and environmental supports and constraints that patients face each day when recommending the best treatment strategy ¹⁵. These patient typologies can help recognize a resistance towards self-management and discover the causes of the resistance. A developed assessment is essential to understand the patient’s perspective and to identify barriers to better individualize self-management support.

Strengths and limitations

A strength of this study is that in this sample, we interviewed nurses working within primary and secondary care and with multiple chronic conditions to provide a broader view of self-management in practice. Additionally, participant characteristics were varied in terms of background, age and experience. This study, however, solely reflects the nurses’ perspectives in applying and tailoring self-management, so this investigation was mainly explorative and was performed in a small sample. A limitation of this study is that the conclusions are based on interviews with nurses who described their practice.

Further research should include observational research of how nurses actually assess chronic patients and how this assessment influences their decision making regarding specific self-management approaches. In addition, research should focus at specific patient characteristics that influence success of self-management support and patients' perception on how nurses carry out self-management. Another limitation is that the study sample might be biased because nurses with an overall positive attitude towards self-management are more likely to have responded to the e-mail request for participants, although various attitudes toward self-management were reflected in this sample.

Conclusions

Nurses' perspectives on self-management appear to greatly influence the way patients are assessed and how self-management is individualized in routine care. Nurses assess patients using various procedures ranging from explicit and extensive assessments to more implicit assessments. Most nurses aim to discover patients' motivation, capacity and mindset instead of specific patient or disease characteristics, whereas other nurses do not have a clear aim to discover possibilities or barriers for self-management. Being able to distinguish between unmotivated patients, patients with limited capacities and oblivious patients can help to overcome patient resistance to achieve more individualized and effective self-management. However, knowledge on more specific patient or disease characteristics and how they influence decision-making is still lacking. This study highlights the need for improved nursing education on the concept of self-management and on performing systematic assessments to be able to respect and respond to the unique wishes and special needs of an individual patient. Scientific efforts are needed to identify the key elements of these assessments guiding tailored self-management. Subsequently, guidelines and education should be developed to facilitate nurses to tailor their care.

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Supplement 1: Interview guide:

Identifying the perceptions of nurses on self-management.

1. What are the first three things that come to mind when you think about self-management?
2. How would you describe self-management?
3. What role has self-management within your consultations?
4. Can you name some examples of self-management tasks?
5. What do find difficult and what is easy in supporting self-management?
6. What role has self-management in your practice/department?
7. What is your aim with self-management support?
8. How do you feel about self-management?
9. What is your role in providing self-management support?
10. What is the patient's role in applying self-management?
11. Is every patient a candidate for self-management? Why?

Identifying factors that might influence the success of self-management.

12. Who are patients of whom you feel they will not be good at performing self-management?
13. How do you adapt care do these patients?
14. What are barriers for self-management?
15. Do you experience any personal barriers to support self-management?
16. Could you characterize a patient who you feel will be good at performing self-management?

Understanding how nurses assess chronic patients concerning the potential of self-management.

17. Could you describe how you get an impression of a patient?
18. On thinking of the patient in front of you during consultation; what are things you notice (e.g. appearance, attitudes)?
19. What patient information do you need to be able to adjust self-management support to an individual patient?
20. Are you consciously assessing a patient or does it go naturally? How important is that assessment?

Understanding how nurses tailor their care concerning self-management

21. When you think about your impression of the patient; how would you adjust care accordingly?
22. What are possibilities to adjust care to an individual patient?



5

Perceptions of self-management in primary care:
a cross-sectional survey study.

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Under review

Abstract

Background: Self-management support is increasingly provided in primary care settings. Perceptions of primary care providers regarding self-management support and of what patient characteristics they think influence the success of self-management support are expected to guide their decisions regarding the extent to which a patient is exposed to self-management.

Objectives: This study aims to explore the perceptions of general practitioners (GPs) and practice nurses (PNs) about self-management support and patient-related factors that can influence the success of self-management support. Furthermore, we will explore differences in perceptions of GPs and PNs.

Method: Between March and June 2014, data was collected through a self-administered online survey set out among primary care providers in the Netherlands.

Results: In total, 272 respondents completed the survey (114 GPs and 158 PNs). The majority of care providers see their role in self-management support as mainly coaching the patient. Most providers aim to stimulate patients to take responsibility for their health behaviour and treatment. Differences between GPs and PNs exist mostly in that PNs more often provide self-management support. Key patient-related factors for successful self-management support, as perceived by both providers, were motivation (93.2%), knowledge of disease (82.6%), educational level (80.4%), self-efficacy (77.2%) and patient-provider relationship (60.3%).

Conclusion: This study provides new insights in perceptions of care providers on self-management support in primary care which can improve and support the implementation of self-management. Furthermore, key patient-related factors influencing success of self-management support were explored. Future studies should evaluate whether these patient factors also influence the decision making of care providers regarding the provision of self-management support.

Introduction

Globally, the number of people with one or more chronic diseases is increasing with huge impact on health care systems worldwide. To safeguard quality, continuity and affordability of care, in the Netherlands and many other countries, chronic care made a gradual transition from secondary to primary care and from primary care to self-care. Also a shift of chronic care from the general practitioner (GP) towards the practice nurse (PN) is taking place. In chronic disease management, self-management support, induced by the chronic care model, has become increasingly important¹. Health professionals provide self-management support to assist the patient in managing their condition². Considering that self-management for patients entails managing the symptoms, treatment, physical and psychosocial consequences and lifestyle changes related a chronic condition³, care providers need knowledge, tools and skills to be able to assess their patients' needs and support them in self-management.

Self-management support is currently embedded in most national and international chronic care guidelines and GPs and PNs both play a key role in self-management support. However, recent studies indicate that self-management is not (yet) an integral part of daily practice and perceptions regarding the provision of self-management support substantially vary between providers^{4,5}. Van Hooft et al. stated that different perceptions of nurses also led to differences in self-management support⁶. Therefore, it is important to know the perceptions of care providers on different aspects of self-management support and what self-management activities are taking place in primary care.

Even though self-management interventions have shown to be effective there is a substantial variance in effectiveness⁷⁻⁹. Therefore, tailoring self-management to the specific needs and preferences of the patient might be the key to effective implementation of self-management support¹⁰. What care providers perceive as important factors for the success of self-management support will influence whether certain patient factors will be assessed and whether self-management support will be provided accordingly. Which patient factors are perceived to be of influence in the success for self-management support and whether there are differences in the perceptions of GPs and PNs is unknown. Other factors such as age and work experience could also influence these perceptions and (clinical) decision making¹¹. Since male and female professionals have different communication styles¹², gender could also be of influence on perceptions of patient-related factors.

Objectives

The primary aim of this study is to explore how GPs and PNs perceive self-management support, more specifically we will explore (1) perceptions about the importance of self-management support, their role in self-management support and their aim with self-

management support, and (2) which self-management activities are currently taking place in practice and which five self-management activities they find most important in self-management support. Furthermore, we will explore which patient-related factors they think influence the success of self-management support. The secondary aim is to explore differences between GPs and PNs in their perceptions of self-management support and whether certain care provider characteristics influence their perceptions on patient-related factors.

Methods

Design and participants

A descriptive cross-sectional study was conducted among general practitioners, final year GP trainees, and PNs working in general practices in the Netherlands. Participants were approached by regional primary health care organizations, the General Practice Specialty Training institutes in the Netherlands and by a mailing from the Dutch Nurses Association. Participants were recruited between March – June 2014.

Data collection

Data was collected through an online questionnaire. The questionnaire was developed for the study purpose by the research team, with scientific and practical expertise in nursing and primary care. Content was based on a thorough review of the literature combined with expert consultation. The questionnaire was pilot-tested by three GPs and three nurses. To assess face and content validity of the questionnaire, they assessed the questions for clarity, relevance, completeness and monitored the time to complete the questionnaire. The validation process did not require substantial changes of the questionnaire, only some practical suggestions were adopted. The questionnaire could be completed within 10 minutes.

In the first part of the questionnaire, several characteristics of the care providers were assessed: sex, age, province, environment (rural/urban), type of practice (single or multiple partner practice), profession, years of work experience and additional relevant courses (i.e. self-management course or motivational interviewing course) followed. Subsequently, three multiple choice questions addressed the care provider's perception of the importance of self-management support, their role in self-management support, and their aim with providing self-management support. Furthermore, they were asked to choose the five most important self-management support components from a list of 19 pre-defined components which are all described in the literature as self-management support component. In addition, they were asked to indicate the extent to which these activities are applied in clinical practice: 'never'; 'sometimes'; 'most of the time' or 'always'. In the final part, care providers were asked to choose (from a list of 15 factors) patient-related factors they thought would influence the success of self-management

support. Subsequently, they ranked the five most important factors from 1 to 5, where 1 represented the most important factor.

Data analysis

The chi-square test was used for analysing differences between GPs and nurses. Logistic regression analyses were performed to explore whether provider characteristics (gender, age, work experience, profession and practice type) influence the perception of the importance of patient factors for the success of self-management. Depending on the mean and the distribution of the number of respondents, the cut-off point for age was determined based on the median age of the care providers. Comparisons with a p-value <0.05 were considered statistically significant. All statistical procedures were performed using SPSS version 22.0 for Windows¹³.

Results

A total of 272 respondents completed the questionnaire, including 114 GPs and 158 nurses (response rate approximately 10%). Of the 114 GPs 23% were final year GP trainees. Table 1 provides an overview of the baseline characteristics.

Table 1. Baseline characteristics of participating general practitioners and practice nurses.

		<i>General practitioner (n=114)</i>	<i>Practice nurse (n=158)</i>
Gender	Male	49 (43.0%)	6 (3.8%)
	Female	65 (57.0%)	152 (96.2%)
Age		47.2 ± 11.7	46.0 ± 10.2
Years in function		16.0 ± 10.6	7.3 ± 4.3
Years working in patient care			23.1 ± 10.7
Practice type	Single	28 (24.6%)	41 (25.9%)
	Duo	40 (35.1%)	44 (27.8%)
	Group	46 (40.4%)	73 (46.2%)
Practice location	Big city (>100.000 citizens)	37 (32.5%)	32 (20.3%)
	City (30.000-100.000 citizens)	36 (31.6%)	52 (32.9%)
	Small city (10.000-30.000 citizens)	24 (21.2%)	51 (32.3%)
	Small town (<10.000 citizens)	17 (14.9%)	23 (14.6%)
Training in motivational interviewing		25 (21.9%)	111(70.3%)
Self-management course		9 (7.9%)	58 (36.7%)

GP= General practitioner, PN= practice nurse

Perceptions of self-management support regarding importance, care providers' role and their aims

The majority of care providers stated that self-management support was important for the quality of chronic care (GPs 64%, PNs 52.5%, p-value 0.19), results are shown in Table 2. On asking how care providers consider their role in supporting self-management, the majority thought their role was mainly coaching (GPs 59.6% and PNs 65.2%, p-value 0.16). The main aim with providing self-management respondents reported as giving the patient an active role and responsibility in his/her treatment and health behaviour (GPs 56.1%, PNs 73.3%, p-value 0.03). However, nurses provided self-management support more often with the aim to give the patient an active role and responsibility in treatment and health behaviour than GPs. GPs more often than nurses stated that their aim with self-management support is to ameliorate the quality of life and the quality of care for patients.

Table 2. Perceptions of self-management support regarding importance, care providers' role and their aims

	Total N (%)	GPs N (%)	PNs N (%)
How do you feel about self-management support in chronic care?			
I think it is important to improve the quality of chronic care	156 (60%)	73 (64%)	83 (57%)
I think it is important in reducing the workload	3 (1%) 85 (33%)	2 (2%) 30 (26%)	1 (1%) 55 (37%)
I think it is important for certain patients but not for all patients	16 (6%)	9 (8%)	7 (5%)
I think the importance of self-management support is overrated.			
As care provider you can have different roles in supporting self-management to a patient. How would you consider your role?			
Mainly to educate/inform patients	55 (21%)	26 (23%)	29 (20%)
Mainly to coach patients	180 (69%)	73 (64%)	107 (73%)
Mainly to motivate patients	25 (10%)	15 (13%)	10 (7%)
What is your main aim with providing self-management support?			
To improve health outcomes and quality of life of patients	70 (27%)	39 (34%)	31 (21%)
Providing effective care (e.g. reducing hospital admissions or reducing consultation number)	12 (5%) 171 (66%)	6 (5%) 64 (56%)	6 (4%) 107 (73%)
To give the patient an active role and responsibility in his/her treatment and health behavior	3 (1%) 4 (1%)	3 (3%) 2 (2%)	0 (0%) 2 (2%)
I do not have a main purpose, I follow the current trend			
I do not provide self-management support			

GP= General practitioner, PN= practice nurse

Most often applied components of self-management support

Self-management components that were stated to be applied in practice are shown in Table 3. Nurses apply most self-management components more often than GPs except for providing a delayed prescription. Additionally, we asked which 5 components of this list care providers perceived as most important in self-management support. For GPs the 5 most frequently mentioned components were increasing understanding of the disease (59.6%), helping patients take ownership in their care (52.6%), establishing common goals with respect to treatment (52.6%), encouraging patients to adjust medication dosage guided by symptoms (43.0%), and stimulating medication adherence (40.4%). Nurses perceived the following components as most important: increase understanding of the disease (71.5%), establish common goals with respect to treatment (60.1%), help patients take ownership of their care (46.8%), teach required skills to the patient (46.8%) and apply motivational interviewing (38.6%).

Table 3. Frequency of self-management components that are performed in clinical practice

<i>Self-management activities</i>		<i>never</i>	<i>sometimes</i>	<i>usually</i>	<i>always</i>
Increase understanding of the disease*	GP	1%	3%	48%	48%
	PN	0%	1%	23%	76%
Encourage smoking cessation	GP	1%	6%	50%	43%
	PN	0%	3%	43%	54%
Encourage exercising*	GP	1%	9%	59%	31%
	PN	0%	1%	43%	56%
Stimulating medication adherence*	GP	2%	10%	63%	25%
	PN	0%	2%	28%	70%
Encourage diet adherence*	GP	2%	21%	60%	17%
	PN	0%	7%	49%	44%
Encourage self-recording measured values*	GP	2%	23%	62%	13%
	PN	3%	12%	49%	36%
Make the patient responsible for contacting the GP or nurse in case of problems	GP	3%	26%	49%	22%
	PN	1%	19%	49%	31%
Establish common goals with respect to the treatment*	GP	5%	34%	53%	8%
	PN	0%	23%	59%	18%
Encourage self-monitoring of symptoms	GP	4%	28%	58%	10%
	PN	3%	25%	50%	22%
Apply motivational Interviewing*	GP	4%	53%	39%	4%
	PN	1%	20%	65%	14%
Teach required skills to the patient*	GP	8%	48%	35%	9%
	PN	1%	23%	52%	25%
Give information brochures	GP	4%	35%	50%	11%
	PN	0%	38%	51%	11%
Help patients take ownership of their care*	GP	6%	50%	39%	5%
	PN	2%	35%	53%	10%
Create responsibility for making regular follow-up appointments	GP	7%	43%	39%	11%
	PN	9%	47%	39%	5%
Encourage patients to adjust medication dosage guided by symptoms	GP	7%	65%	25%	3%
	PN	8%	54%	31%	7%
Encourage use of E-health	GP	19%	56%	25%	0%
	PN	26%	58%	14%	2%
Give delayed prescription*	GP	11%	75%	12%	2%
	PN	69%	27%	3%	1%
Offer self-management workshops/courses*	GP	67%	26%	7%	0%
	PN	51%	43%	5%	1%
Organize group interventions and consultations aimed at self-management	GP	74%	23%	3%	0%
	PN	74%	22%	3%	1%

GP= General practitioner, PN= Practice nurse *Statistically significant difference between GPs and PNs in frequency of applying self-management support component

Patient-related factors

Patient-related factors that were perceived as important factors for success of self-management support are shown in Figure 1. The top 5 ranking of factors were (1) motivation, (2) knowledge of the disease, (3) education level, (4) self-efficacy and (5) patient-provider relationship. On average, care providers considered almost eight patient factors to be of influence on self-management success (GPs considered a mean of 8.3 factors and PNs 7.5 factors to be of influence). Furthermore we explored whether certain provider characteristics would be of influence on which patient factors they think will influence the success of self-management (Table 4). Profession had the highest impact on the choice for certain patient factors, while practice type did not influence their choice. Males consider knowledge of disease and self-efficacy as less important than females, younger care providers think social support is less important than older care providers, and care providers with <5 years of work experience are more likely to think that age is an important factor and think that self-efficacy is less important than care providers with more work experience.

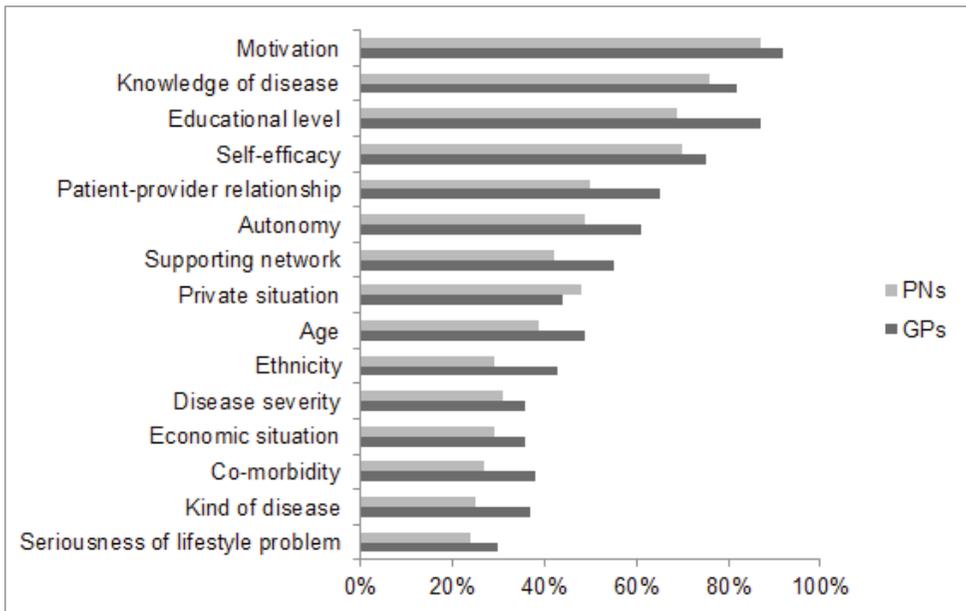


Figure 1. Patient-related factors that influence the success of self-management support according to primary care providers

Table 4. Logistic regression of how care provider characteristics influence the perception of the importance of patient factors for the success of self-management.

Patient factors	Provider characteristics	OR (CI)
Knowledge of the disease	GP vs. PN	2.7 (1.2-6.1)
	Male vs. female	0.2 (0.1-0.6)
Educational level	GP vs. PN	2.9 (1.5-5.5)
Self-efficacy	GP vs. PN	1.9 (1.0-3.8)
	Male vs. female	0.4 (0.2-0.8)
	<5 yrs experience vs. >5 yrs experience	0.5 (0.3-0.9)
Patient-provider relationship	GP vs. PN	1.8 (1.1-3.0)
Autonomy	GP vs. PN	1.8 (1.1-3.0)
	Younger vs. older age	0.6 (0.4-1.0)
Supporting network	GP vs. PN	1.7 (1.0-2.8)
	Younger vs. older age	0.5 (0.3-0.8)
Age	<5 yrs experience vs. >5 yrs experience	2.8 (1.6-4.9)
Ethnicity	GP vs. PN	1.9 (1.1-3.1)
Co-morbidity	GP vs. PN	1.6 (1.0-2.8)
Kind of disease	GP vs. PN	2.4 (1.3-4.4)

OR= Odds ratio, CI= confidence interval. The model included 5 provider characteristics: profession (GP=general practitioner vs. PN=practice nurse), gender (male vs female), age (younger than median age vs older), Work experience in current profession (<5 years experience vs > 5 years), practice type (solo vs. group practice).

Discussion

This study found that two-third of the primary care providers share their perceptions regarding the importance of self-management support, and their aim and role in providing it. Overall, most self-management activities are more often applied by nurses. The most important patient-related factors for successful self-management support as perceived by all care providers are motivation, knowledge of disease, educational level, self-efficacy, and patient-provider relationship.

The majority of care providers stated that self-management is important for the quality of chronic care. About a third stated that it is important for a subgroup of patients but not for everyone. These opinions correspond with current evidence from meta-analyses that showed that quality of chronic care is indeed improved and that self-management is associated with positive results in certain patients but certainly not in all patients⁷⁻⁹.

The role care providers play in self-management support was by the majority perceived as mainly coaching while a minority thought their role was to educate or to motivate the

patient for self-management. In literature, the role as coach is seen as the part that a care provider needs to play, mere education is important but insufficient to increase self-management competences and achieve behaviour change¹⁴.

In this study lifestyle components were stated to be often applied, therefore, encouraging lifestyle change seems to have become a standard element during consultations. However, since we only relied on self-reported data we cannot be sure to what extent this is truly applied. Literature on audio- and videotape recorded consultations showed that discussions on lifestyle topics take place but counselling competences could be improved¹⁵⁻¹⁷.

Even though the majority of care providers stated that their aim with self-management is to give the patient an active role and responsibility and that they see their role as mainly coaching, we found that the activities 'help patients take ownership of their care' and 'teaching skills' are not that frequently applied. The role as coach is defined by Lindner and colleagues as an interactive role to support a patient to be an active participant in the self-management of a chronic illness¹⁸. This suggests that 'help patients take ownership of their care' should be part of a coaching role. Furthermore, supporting patients in these areas can be seen as a prerequisite for becoming a good self-manager that can take an active role and responsibility in his/her treatment and health behaviour. Care providers already consider these self-management activities as important activities in self-management support; however, in routine care they should be more frequently applied.

From the baseline characteristics it was clear that few care providers have had education in self-management support. This supports the need for intensifying education for care providers in the field of self-management which was also concluded by Lake and Staiger in their qualitative research investigating views of health professionals their use of chronic disease self-management (CDSM) in the workplace¹⁹. Provider education is mentioned to be an effective implementation strategy for guideline implementation and this can be lacking especially on the topic of self-management.

E-health use, self-management courses and group consultations were very rarely applied. Given the emerging technological developments it is to be expected that e-health will get a more prominent place in primary care in the near future.

Most self-management activities are more often applied by nurses, especially motivational interviewing and teaching skills. This is probably due to the shift in chronic care from the GP to the nurse and nurses having more consultation time to be able to provide chronic care. Also nurses more often have had motivational interviewing courses. Previous studies showed that nurses considered it their role to provide self-management support^{4,5} and general practitioners also considered it the role of the nurse²⁰.

The most important patient-related factors for successful self-management support as perceived by care providers were motivation, knowledge of disease, educational level,

self-efficacy and patient-provider relationship. Motivation and self-efficacy are well-known factors which correspond with behaviour change theories described by Prochaska and Bandura^{21,22}. Knowledge is often seen as a prerequisite for self-management²³ although not consistently linked to disease outcomes²⁴. The patient-provider relationship is associated with better self-management adherence²⁵ and a low educational level was identified as a factor that increases the likelihood for success of self-management interventions²⁶.

Care providers on average considered eight patient factors to be of influence on self-management. Literature shows that many patient factors influence patient self-management^{23,27}. Whether care providers routinely assess all these factors is not known from this study but they do seem aware that many factors can be of influence.

Based on a national registration of GPs and PNs we concluded that our sample of GPs and PNs was representative. We included some GPs that are affiliated with the General Practice Specialty training institutes and GP-trainees, who might be more innovative and may be a step further in the implementation of self-management compared to other GPs. This could have influenced the results in the direction of a more positive attitude toward self-management support. The response rate of around 10% was relatively low, however, this was an estimate and this rate is not uncommon for a survey request by e-mail²⁸. Care providers receive quite a lot of research requests and our sample of 114 GPs and 158 nurses was considered adequate for our exploration.

Since the questionnaires were self-reported we cannot be sure whether perceptions were influenced by socially desirable answers and whether these results correspond with actual provision of self-management support in daily practice.

Conclusions

This study explored perceptions of care providers on different aspects of self-management support in primary care. In line with the current shift in chronic care provision from GP to practice nurse, nurses more often provide self-management support than GPs. Although considered as important activities; ‘help patients take ownership of their care’ and ‘teaching skills’ may need more attention in providing self-management support and may request more education for care providers. Future studies on how self-management support is provided are needed to determine the need for improvement. E-health use in supporting self-management is still uncommon suggesting room for implementation of effective e-health strategies. Moreover, this study provides information on which patient-related factors are perceived as important for successful self-management support. Future studies should evaluate whether these factors actually do influence the decision making of care providers regarding the provision of self-management support.

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6

Patient factors that influence decision-making in self-management support: A clinical vignette study

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Abstract

Background and aim Self-management support is nowadays an integral part of chronic care guidelines. The success of self-management interventions varies between individual patients, suggesting the need for tailored self-management support. Understanding the role of patient factors in current decision-making of health professionals can support future tailoring of self-management. The aim of this study is to identify the relative importance of patient factors in health professionals' decision-making for providing self-management support.

Method A factorial survey was presented to primary care physicians and nurses. The survey consisted of clinical vignettes (case descriptions) in which 11 patient factors were systematically varied. Each care provider received a set of 12 vignettes. For each vignette they decided whether they would give this patient self-management support and whether they expected self-management support to be successful in this patient. The associations between respondent decisions and the patient factors were explored by means of mixed ordered logit regression.

Results The survey was completed by 60 general practitioners and 80 nurses. Self-management support was not likely to be provided in a third of the vignettes. The most important patient factor in the decision to provide self-management support as well as in the expectation that self-management support will be successful was motivation, followed by patient-provider relationship and illness perception. Other factors, such as depression or anxiety, education level, self-efficacy and social support, had a small impact on decision-making. Disease, disease severity, knowledge of disease, and age were relatively unimportant factors.

Conclusion This is the first study that explored the relative importance of patient factors in decision making and expectations regarding the provision of self-management support to chronic disease patients. By far, the most important factor considered is patient's motivation; unmotivated patients are less likely to receive self-management support. Future tailored interventions should incorporate strategies to enhance motivation in unmotivated patients. Furthermore, care providers should be better equipped in stimulating motivational change in their patients.

Background

In the Netherlands, one third of the older population has one or more chronic disease¹. Adequate self-management behavior may favor individuals living with a chronic disease². In the guidelines for many chronic diseases self-management support is incorporated to help the patient “manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition”³. Chronic care is increasingly embedded in primary care. In addition, over the past decade care provision is shifting from the general practitioner (GP) to the practice nurse (PN), especially for diabetes type 2, COPD and cardiovascular disease⁴.

Even though self-management support is now an integral part of guidelines and promising results of self-management interventions are seen, self-management interventions are not effective in every patient⁵⁻⁷. This implies that one size fits all interventions are only successful in subgroups of patients. Tailoring self-management to the specific needs of a patient is expected to improve self-management efficacy⁸ and therefore to improve the effect size of interventions.

To move towards more tailored solutions knowledge is required on what patient factors are currently taken into account by care providers in providing self-management support. Little is known on how implicit decisions, such as providing self-management support, are made in practice by GPs and nurses. In previous survey study we investigated which patient factors care providers considered important for the success of self-management, we found that motivation, knowledge of disease, educational level, self-efficacy and patient-provider relationship were the most frequently considered factors⁹. In a previous qualitative studies nurses explicitly mentioned patient factors, such as motivation and capacity, to affect their decision for providing self-management support^{10,11}. What the relative importance of these factors is in the actual decision-making process is unknown. As mentioned by Ludwick et al., the insight of clinicians in their decision-making process is often limited¹². Simulating clinical practice can be a good way to find out how decisions are made in clinical practice.

The aim of the clinical vignette-study is to investigate what the relative importance is of patient factors in the decision to provide self-management support and in the expectation that self-management support will be successful in a patient. Since PNs are taking over an important part of chronic care differences in decision-making of GPs and PNs are explored.

Methods

Design

This is a cross-sectional study with a factorial survey design, in which respondents are asked to evaluate clinical vignettes¹³. A vignette is a brief, written case history of a fictitious patient based on a realistic clinical situation¹⁴. Vignettes are found to be a valid tool to simulate clinical practice and to measure the quality of care in clinical practice¹⁵. In our vignettes the factors of interest (i.e. the patient factors) were varied in a systematic way to explore decision-making and the importance of each factor. Subsequently, GPs and PNs were presented with a sample of vignettes and answered questions that explored what they would decide when presented with the actual patient.

Participants

The study population consisted of general practitioners (GPs), last year GP trainees and practice nurses (PNs) working in general practices in the Netherlands. Potential participants were approached through regional primary health care organizations, the General Practice Specialty Training institutes in the Netherlands, and by a mailing from a national PN network.

Data Collection

Data were collected through an online questionnaire. Participants were recruited from March – June 2014 for a preceding survey. Participants from this survey were asked to be approached for a follow-up study and when they consented they were asked for their email addresses. From July –October 2014 the clinical vignette survey was completed. Three reminders were sent in case of non-response.

The survey consisted of 12 clinical vignettes in which eleven patient factors were systematically varied. Since definitions and perceptions of what self-management support entails can vary substantially between professionals we defined self-management support as follows: *Self-management support consists of transfer of information and a minimum of two of the following components: active stimulation of symptom monitoring, medication management, education in problem solving skills(i.e. self-treatment such as managing acute exacerbations, resource utilization and stress/symptom management) and enhancement of medication adherence, physical activity, dietary intake or smoking cessation*¹⁶.

GPs and PNs were instructed to read each vignette, as if it was an actual patient consultation, and were asked to rate the likelihood of providing self-management support to this patient on a 5-point Likert scale (very unlikely – very likely). Subsequently, they were asked how successful they thought self-management support would be in this patient. Answering options were categorized on a 5-point Likert scale, from not at all successful to very successful.

Selection of patient factors

Potential patient factors that could be of influence on self-management capacity of patients were comprehensively searched in the literature and discussed within the research team consisting of experts in nursing, general practice, and self-management. A selection of 15 factors, that were thought to be clinically relevant and of potential influence on the decision for self-management support by the research team, was presented in a survey to GPs and PNs. They were asked which patient factors they considered important for the success of self-management and whether they missed any factors in the list provided. This validation step confirmed the 15 factors from the literature. Illness perception and depression were not described and not validated in the survey, however, in our recent study¹⁷ these factors were found to be associated with activation for self-management. Therefore, we decided to add illness perception and anxiety and depression disorders to the list. Subsequently, we aimed to reduce our list of 17 patient factors for our final selection because a reader cannot process that many information in a vignette. Therefore, we weighted the factors based on their importance in the survey study, in the literature, and discussed possible overlap of the factors in an expert meeting and reduced the list to 11 factors (Table 1.).

Table 1. Factors and categories included in the vignettes.

Patient Factors	Categories (Levels)
Age	40 years old 60 years old 80 years old
Education level	High education level Medium education level Low education level
Disease	COPD (Chronic obstructive pulmonary disease) DM II (Diabetes mellitus type 2)
Knowledge of disease	Has sufficient knowledge of the disease Has insufficient knowledge of the disease
Illness perception	Having a realistic illness perception Having a non-realistic illness perception
Disease burden	No symptoms Mild symptoms Severe symptoms
Social support	Having social support at home No social support at home
Self-efficacy	Sufficient self-efficacy Low self-efficacy
Motivation	Motivated for self-management Not motivated for self-management
Anxiety or depressive disorder	Present Absent
Patient-provider relationship	Good patient-provider relationship Poor patient-provider relationship

The factors level of autonomy, social economic status, gender, ethnicity, comorbidities in general, and private problems were left out because they were considered least important. We chose the two most prevalent chronic conditions that in the Netherlands are managed by both the GP and the PN, namely chronic obstructive pulmonary disease (COPD) and diabetes mellitus (DM).

For each of the patient factors we defined categories. Since few categories are preferred in order to keep the total number of possible vignettes small we restricted this to 2 or 3 categories. Our final selection of factors and categories is shown in Table 1.

Selection of vignettes

The full factorial design combines all the levels of one factor with all the levels of the other factors. With the selected factors and factor levels, 6912 vignettes ($2^8 \cdot 3^3$) were created. As it would be too burdensome for respondents to complete all vignettes, an efficient selection had to be made (i.e. a fractional factorial design). Prior to selecting the fractional factorial design, unrealistic vignettes were removed from the full factorial design. These comprised vignettes representing patients with insufficient knowledge of his/her illness while having a realistic illness perception and vignettes representing patients 40 years of age who suffered from COPD. In R Cran for Windows using the AlgDesign package, 96 vignettes were selected by applying the Federov Algorithm^{18,19}. We decided to only take main effects into account in the analyses, leaving us with an explained variance between 70% to 90%²⁰. The quality of the resulting design was evaluated by means of the G efficiency parameter which ranges between 0 (inefficient design) and 1 (efficient design)¹⁹. The resulting design had a G efficiency of 0.96 and was considered efficient. The selected vignettes were subsequently allocated into eight blocks each comprising 12 vignettes. By dividing vignettes into blocks we ensured that the main effects could be estimated within each block. The loss of efficiency due to blocking appeared to be limited as the geometric mean of efficiency was 0.996.

Sample size was based on the assumption that 6 respondents per vignette are required to reliably perform the analyses and retrieve valid results²⁰. Since we aimed to perform the analyses separately for GPs and PNs and have 8 blocks of vignettes, we needed (8*6) 48 GPs and 48 PNs (per block a minimum of 6 GPs and PNs is preferable). Each care provider received a randomly allocated set of 12 vignettes. The randomisation procedure was stratified for type of primary care provider (GP, PN).

Case description of clinical vignette

The vignette text was written by one of the research team members and subsequently discussed in the research team to make sure that the vignette was as realistic as possible. Vignettes were piloted to ensure clarity and realism. An example of a vignette is shown in Table 2.

Table 2. Example of a clinical vignette used in the survey.

Patient X is **40-years old**, has a **medium education level** and comes to see you for a **diabetes check-up**. The patient experiences currently **no diabetes related symptoms**. You do **not experience a good patient-provider relationship**. The patient has **sufficient knowledge of the disease** and has a **realistic illness perception**. The patient **has social support at home**. The patient is **not motivated for self-management** and has **low self-efficacy for self-management**. The patient does **not have an anxiety or depressive disorder**.

Data analyses

Descriptive statistics were used to describe respondent characteristics and were obtained using SPSS version 22.0 for windows²¹. Following analyses were performed using R-cran for windows¹⁸. The associations between respondent choices and the factors were explored by means of mixed ordered logit regression. This model was chosen since our outcome variables are ordinal and each respondent evaluated 12 vignettes, therefore their answers were clustered. The model was created by entering all factors at the same time into the model. This is because respondents were also presented with 11 factors at a time. The model took into account the panel dimension of the data (respondents completed 12 vignettes each) by including respondent number as a random effect. The main model assumption, which is the proportional odds assumption, was assessed graphically by making line graphs of all the variables and checking them on parallelism (Addendum 1). Although small deviations could be seen, our conclusion was that the proportional odds assumption was met. The model subsequently was the basis for determining the relative importance of the factors. By means of partial log-likelihood analyses, the difference in log-likelihood of the main effects model was compared with models in which one factor was removed. Finally, 95% confidence intervals of the relative importance measures in GPs and PNs were calculated by means of bootstrapping (n=1000).

Results

From the 230 health care providers approached 161 agreed to participate (response rate 70.0%). Out of 1932 vignettes that were presented 1762 were completed (91.2%). Out of 161 respondents, 21 (13%) had incomplete data. Respondents with missing values and the respondents with no missing values did not differ in terms of profession, practice type, gender, age, work experience and in their perception (role, aim and importance) of self-management.

Table 3. Baseline characteristics of participants

		General practitioner (n=60)	Practice nurse (n=80)
Gender	Male	30 (50%)	2 (2.5%)
	Female	30 (50%)	78 (97.5%)
Age		47.1 ± 11.7	45.8 ± 10.5
Years in function		15.6 ± 10.5	7.1 ± 4.4
Practice type	Single	16 (26.7%)	21 (26.3%)
	Duo	24 (40.0%)	27 (33.8%)
	Group	20 (33.3%)	32 (40.0%)
Practice location	Big city (>100.000 citizens)	18 (30.0%)	14 (17.5%)
	City (30.000-100.000 citizens)	18 (30.0%)	30 (37.5%)
	Small city (10.000-30.000 citizens)	16 (26.7%)	26 (32.5%)
	Small town (<10.000 citizens)	8 (13.3%)	10 (12.5%)
Received training in motivational interviewing		14 (23.3%)	60 (75%)

Since respondents with missing values could not see the next vignettes when they did not complete the previous one, the missing values were not linked to the factors. There was enough statistical power to perform the analyses with the complete cases, which is why we chose not to impute the data but to perform complete case analyses. We performed our analyses with 60 GPs and 80 PNs. The baseline characteristics are shown in Table 3.

Relative importance of patient factors

Self-management support was considered unlikely to be provided in 29% of the vignettes and in 46% of the vignettes self-management support was expected to have a low chance of success. The relative importance of the factors is shown in Figure 1 and 2 (a table containing the confidence intervals is available in Addendum 2). Analysis of the relative importance of each attribute showed that motivation was by far the most important factor for the likelihood of providing self-management support (GPs 52%, PNs 59%) as well as in their judgment how successful self-management support would be (GPs and PNs 58%). For GPs illness perception was the next most important factor after motivation with 13% while for PNs the patient-provider relationship was the next important factor with 19%. Type of disease, disease burden, knowledge of disease, and age were considered relatively unimportant factors in both the decision to provide self-management and in estimating the likelihood of success.

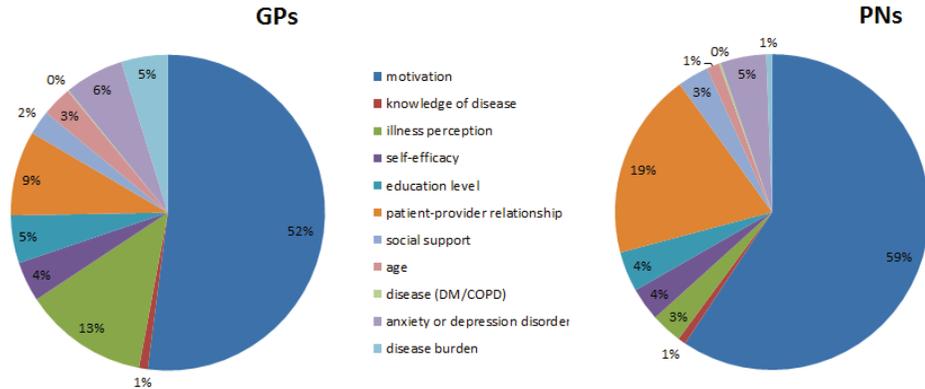


Figure 1. Relative importance of patient factors in providing self-management support

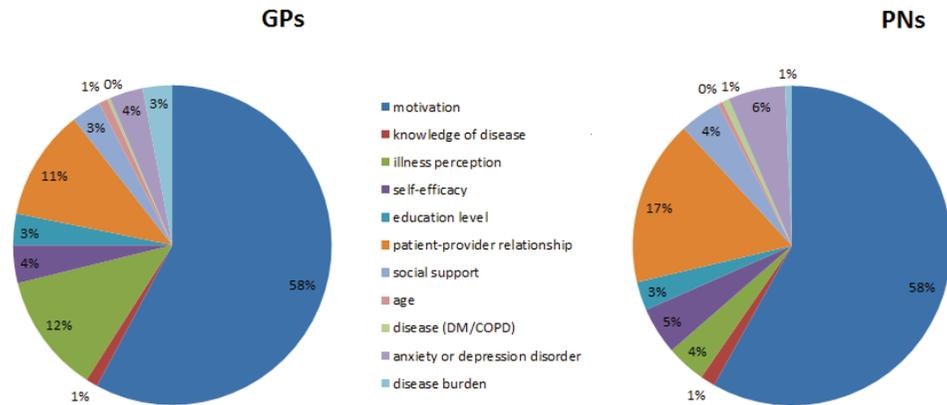


Figure 2. Relative importance of patient factors in judging whether a patient will be successful in self-management

Importance of the categories

Odds ratios (OR) of the factor categories for the decision to provide self-management support are presented in Table 4. The OR represents the average odds that self-management will likely be provided given the factor category, compared to the average odds that self-management will be provided in the absence of that category. Thus, the odds ratio of receiving self-management support of a GP when a patient is motivated is on average 8.34 higher compared to a patient that is not motivated. Except for the factor disease, all factors show a positive OR and are likely to be associated with a higher odds ratio of receiving self-management support compared with the absence of a factor except for type of disease. Overall, there are no significant differences between GPs and PNs in the contribution of factors; motivation shows the highest OR for both. GPs have a higher OR for illness perception, though not statistically significant. Furthermore, PNs more often have an OR of 1 in their confidence interval.

Table 4. Odds ratios of the categories for providing self-management support to a patient based on examination of 64 vignettes by 60 GPs and 80 PNs.

	<i>General practitioner Odds ratio (CI)</i>	<i>Practice nurse Odds ratio (CI)</i>	<i>Total Odds ratio (CI)</i>
Age			
40 years vs. 80 years	1.94 (1.28-2.93)	1.54 (1.08-2.20)	1.68 (1.28-2.19)
60 years vs. 80 years	1.42 (1.02-1.99)	1.17 (0.88-1.56)	1.25 (1.01-1.56)
Education level			
Medium vs. low	1.61 (1.13-2.30)	1.24 (0.92-1.68)	1.37 (1.09-1.73)
High vs. low	2.12 (1.47-3.04)	1.89 (1.39-2.57)	1.95 (1.55-2.46)
Disease DM-II vs COPD	1.08 (0.77-1.50)	1.15 (0.87-1.54)	1.12 (0.90-1.39)
Sufficient knowledge of disease vs. insufficient knowledge of disease	1.38 (0.97-1.97)	1.34 (0.99-1.81)	1.34 (1.07-1.69)
Realistic illness perception vs. non-realistic illness perception	3.41 (2.36-4.92)	1.77 (1.30-2.39)	2.30 (1.83-2.90)
Disease burden			
Mild symptoms vs. no symptoms	1.86 (1.30-2.67)	1.05 (0.78-1.43)	1.32 (1.05-1.67)
Severe symptoms vs. no symptoms	1.97 (1.37-2.82)	1.27 (0.93-1.72)	1.51 (1.20-1.90)
Having social support vs. not having social support	1.55 (1.16-2.08)	1.60 (1.25-2.05)	1.58 (1.31-1.91)
Sufficient self-efficacy vs. low self-efficacy	1.76 (1.31-2.37)	1.63 (1.27-2.10)	1.66 (1.37-2.00)
Motivated for self-management vs. not motivated for self-management	8.34 (5.99-11.6)	8.54 (6.44-11.33)	8.33 (6.73-10.31)
Having no depression or anxiety disorder vs. having a depression or anxiety disorder	1.99 (1.48-2.67)	1.76 (1.37-2.26)	1.83 (1.51-2.21)
Good patient-provider relationship vs. not a good patient-provider relationship	2.28 (1.69-3.08)	3.21 (2.48-4.16)	2.75 (2.27-3.35)

CI= confidence interval, DM-II = Diabetes mellitus type II, COPD= Chronic obstructive pulmonary disease

Table 5 shows the ORs when self-management is considered to be successful in a patient considering the presence of a factor. Being motivated for self-management versus not being motivated is showing highest ORs (GPs OR 16.1, PNs OR 11.0). A statistically significant difference between GPs and PNs is found for illness perception (GPs OR 4.1 (CI 2.8-6.0), PNs OR 2.0(CI 1.5 -2.8)). Overall, odds ratios are higher when considering whether self-management will be successful than the likelihood of providing self-management. Exceptions are education level, in which the OR remains more or less the same, and for age and disease severity the ORs decrease and the association is therefore less strong.

Table 5. Odds ratios of the categories for expecting self-management support to be successful in a patient based on examination of 64 vignettes by 60 GPs and 80 PNs.

	<i>General practitioner Odds ratio (CI)</i>	<i>Practice nurse Odds ratio (CI)</i>	<i>Total Odds ratio (CI)</i>
Age			
40 years vs. 80 years	1.54 (1.01-2.33)	1.29 (0.91-1.85)	1.37 (1.05-1.80)
60 years vs. 80 years	1.13 (0.80-1.60)	1.21 (0.91-1.62)	1.17 (0.94-1.47)
Education			
Medium vs. low	1.55 (1.07-2.23)	1.46 (1.07-1.99)	1.49 (1.18-1.88)
High vs. low	2.06 (1.42-2.97)	1.83 (1.34-2.50)	1.91 (1.51-2.41)
Disease DM-II vs COPD	1.25 (0.88-1.76)	1.32 (0.98-1.77)	1.30 (1.04-1.62)
Sufficient knowledge of disease vs. insufficient knowledge of disease	1.57 (1.09-2.27)	1.54 (1.13-2.11)	1.56 (1.23-1.97)
Realistic illness perception vs. non-realistic illness perception	4.13 (2.83-6.01)	2.04 (1.50-2.78)	2.73 (2.15-3.46)
Disease burden			
Mild symptoms vs. no symptoms	1.59 (1.11-2.30)	1.28 (0.94-1.75)	1.40 (1.10-1.77)
Severe symptoms vs. no symptoms	2.02 (1.40-2.92)	1.33 (0.97-1.81)	1.57 (1.24-1.99)
Having social support vs. not having social support	1.79 (1.32-2.41)	1.82 (1.41-2.35)	1.80 (1.48-2.19)
Sufficient self-efficacy vs. low self-efficacy	1.91 (1.41-2.59)	1.91 (1.48-2.27)	1.91 (1.57-2.32)
Motivated for self-management vs. not motivated for self-management	16.07 (11.10-23.29)	11.02 (8.20-14.81)	12.84 (10.19-16.16)
Having no depression or anxiety disorder vs. having a depression or anxiety disorder	1.85 (1.37-2.50)	2.04 (1.58-2.64)	1.95 (1.60-2.36)
Good patient-provider relationship vs. not a good patient-provider relationship	3.10 (2.27-4.22)	3.42 (2.63-4.46)	3.22 (2.63-3.93)

CI= confidence interval, DM-II = Diabetes mellitus type II, COPD= Chronic obstructive pulmonary disease

Discussion

This study found that in both care providers motivation is the most important factor in deciding to provide self-management support and expecting that self-management support will be successful. For GPs illness perception is the next most important factor and for PNs the patient-provider relationship. All other factors play either a minor or no role in deciding to provide self-management support. Furthermore, this study shows that self-management support would not likely be provided in every patient meaning that not every patient is considered suitable for self-management and certain patients remain unexposed to self-management support.

This final conclusion supports the importance of knowing what factors play a role in decision-making regarding self-management support. From previous research we did expect that motivation would play an important role in self-management support. In a qualitative study nurses mentioned that motivation and capability were most important in self-management support¹¹ and in the prior survey to this study motivation was often mentioned as a factor⁹. Now we know the importance of the factor motivation and that when motivation is not present it is unlikely that self-management support is provided.

The question rises whether it is justifiable to not provide self-management to unmotivated patients or that we should at least give it an attempt. According to the transtheoretical model of behavior change, people need to be guided through several stages of change to increase motivation before they are ready for action²². However, since motivation is such a huge barrier for self-management maybe too much weight is thrown on motivation and health care providers find it difficult to see what causes a patient to be unmotivated. According to the Health Belief Model; perceived susceptibility to and severity of illness, perceived costs and benefits, and self-efficacy explain what motivates a person to engage or not engage in health-related behavior²³. In The Behaviour change wheel it is stated that behaviour is construed as a product of: capability, opportunity and motivation²⁴. These interact with what you can think of as a system. Motivation is the part that determines, given that we have the opportunity to do a variety of things and the capability, what we actually do and how we do it. Many more motivation and behaviour change theories exist, however, the key is that motivation does not stand on its own and Rollnick and colleagues state that “no person is completely unmotivated”²⁵ and ambivalence towards a behaviour should be explored. Motivational interviewing is doing just that since it was defined as “a directive, client-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence”²⁵. Many care providers in the Netherlands have followed a course in motivational interviewing (MI), however, studies show that using MI during routine consultations in primary care is no standard practice (yet) even though MI courses have been followed^{26,27}. MI is not something that is easily learned and mastered. It really requires skills and involves the conscious and disciplined use of specific communication principles and strategies to evoke the person’s own motivations for change²⁸. This would require more intense training of GPs and PNs in motivational interviewing.

GPs also considered illness perception as an important factor. Illness perceptions (ideas/beliefs that patients have about their illness and symptoms) can vary substantially between patients and are important in establishing coping behaviours and illness specific behaviours such as adherence to treatment^{29,30}. Literature suggests that illness perception is important, however, PNs did not seem to consider this as a very important factor. On the other hand PNs considered the patient-provider relationship as quite an important factor. Most mentioned factors that influence how the relationship is, are mutual trust, confidence

in each other and good communication. In a previous study nurses also mentioned that building a strong relationship and mutual trust made a patient more comfortable in sharing personal information and nurses indicated that patients with involved and compassionate nurses would more readily improve their self-management¹¹. In motivational interviewing communication and listening with empathy is seen as a prerequisite for behaviour change²⁵. We also hypothesized that maybe care providers would find it easier to give a patient with whom they have a good relationship responsibility than patients with whom they do not have a good relationship. Why GPs consider illness perception as more important and PNs the patient-provider relationship cannot be concluded from this study. However, both factors can be influenced by exploring illness perceptions and by an open attitude towards patients and good communication skills.

A remarkable finding was that knowledge of disease was not a decisive factor at all. In the previous survey study professionals ranked knowledge of disease second in most influencing factors for the success of self-management, however, this characteristic did not show to be of influence in the vignettes. Furthermore, self-efficacy was also a minor factor in this study while in the previous survey it was ranked fourth most important factor. The well-known self-management programme Chronic Disease Self-Management Program (CDSMP) incorporates strategies suggested by Bandura to enhance self-efficacy to help patients become confident and knowledgeable³¹. And many more self-management programs aim at increasing knowledge of disease and treatment, and self-efficacy. In this study care providers did not consider knowledge of disease and self-efficacy as important factors. Maybe, they are really not of much concern or maybe because they are both well-known factors they are no longer seen as barriers but as something you can influence as a care provider.

Strengths and limitations

To our knowledge this is the first study that explores the relative importance of certain patient factors in decision-making concerning self-management support. Our sample size was adequate to answer our research questions. We used an efficient design to perform an exploration of the patient factors in decision-making. In our clinical vignettes the factors were rather explicit and in clinical practice more nuances are expected. Although this is a limitation of a vignette it more clearly shows the relative importance of factors. We can only conclude what the relative importance is of the factors and we do not know why care providers have chosen them, however, it does give insight in decision-making. We could not take all possible patient factors into account because that would make a vignette unreadable and readers cannot take that many factors into account. The findings are therefore based on our current selection of factors; however, there could be other important factors in decision-making concerning self-management support that we did not take into account in this study.

Conclusion

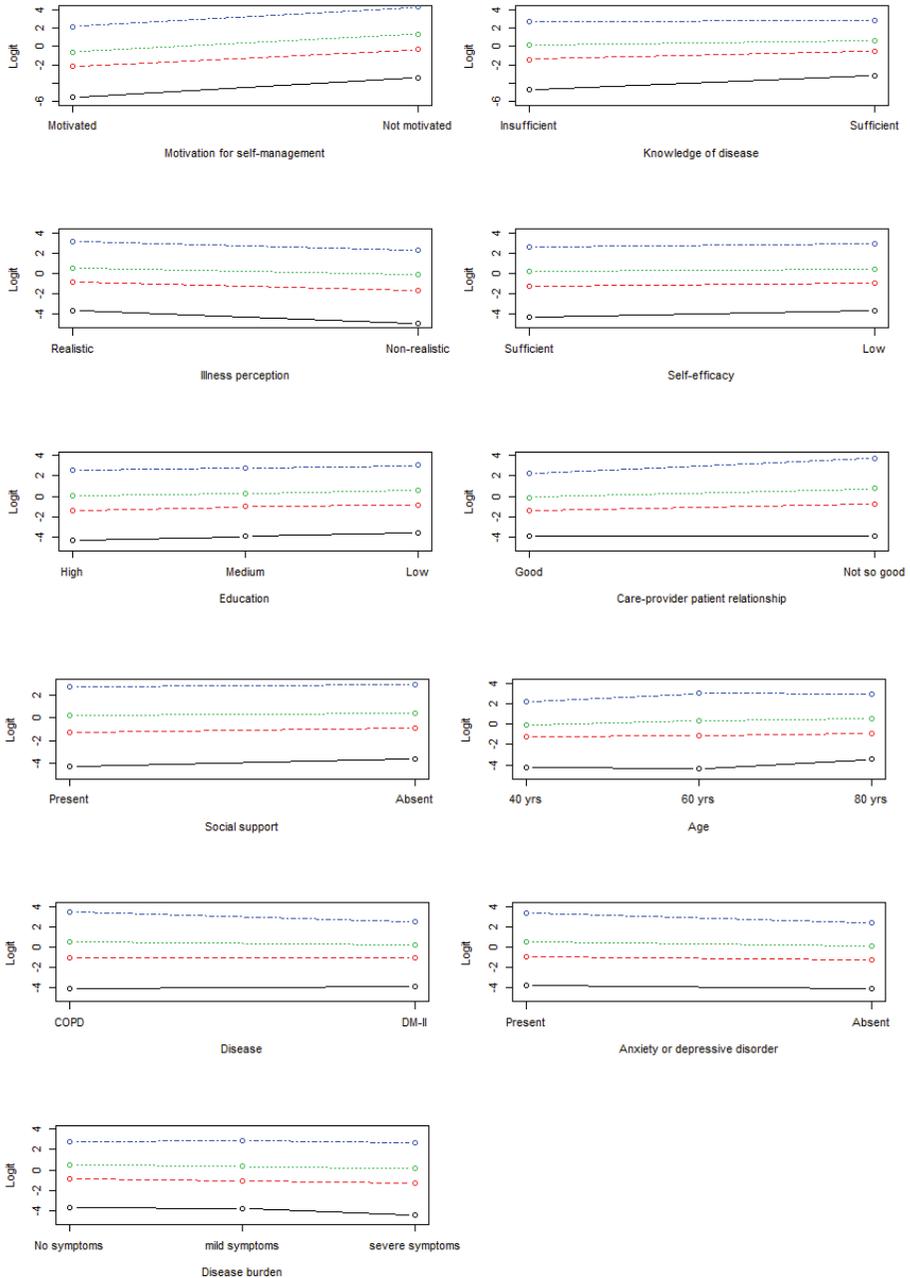
This study shows that patient factors play a role in deciding to provide self-management support because in 30% of the presented cases self-management support was not likely provided. By far, the most important factor is motivation in both the likelihood of providing self-management as well as in expecting that self-management support will be successful in a patient. Unmotivated patients are less likely to receive self-management support. Future tailored interventions should incorporate strategies enhancing motivation in unmotivated patients. Furthermore, care providers need more insight in what causes a patient to be unmotivated and what other factors play a role and how to increase motivation. Increasing motivational interviewing skills of care providers can be a strategy to become better equipped in stimulating motivational change. Few differences between GPs and PNs were seen; although GPs put more importance on illness perception and PNs more on patient-provider relationship. All other factors played a minor or even no role in self-management support. The three patient factors that were most important are all factors that can be influenced by a care provider by increasing awareness, communicating skills and probably consultation time.

In conclusion, in current primary care practice motivation is seen as the most important factor in deciding to provide self-management support and expecting that self-management support will be successful.

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Addendum 1. Graphical test for proportional odds assumption The lines in the graphs represent the different dichotomized models (solid line represents the model not likely to very likely to give SMS vs very unlikely to give SMS, the dashed line represents the model somewhat likely to very likely to give SMS vs not likely and very unlikely to give SMS and so on for the dotted and the dash-dot line).

Addendum 2. Relative importance of factors

		<i>Providing SM support Log likelihood(CI)</i>	<i>Patient will be successful Log likelihood(CI)</i>
Motivation	Total	218.1	288.8
	GP	90.9 (68.9-113.9)	137.5 (110.4-171.0)
	PN	127.6 (102.0-160.0)	151.1 (125.6-183.9)
Patient-provider relationship	Total	54.3	68.5
	GP	15.1 (6.5-28.7)	26.7 (14.4-42.4)
	PN	41.1 (25.6-62.4)	43.7 (26.5-64.3)
Illness perception	Total	25.3	35.5
	GP	22.3 (11.0-38.1)	28.8 (16.8-44.5)
	PN	6.8 (1.5-16.5)	10.5 (3.5-22.6)
Having a depression or anxiety disorder	Total	19.8	23.0
	GP	10.6 (3.4-22.5)	8.2 (2.3-18.0)
	PN	10.0 (3.3-20.8)	15.1 (7.1-27.9)
Education level	Total	16.1	14.8
	GP	8.6 (2.6-20.7)	7.6 (2.5-18.3)
	PN	8.8 (2.8-20.3)	7.5 (2.2-18.2)
Self-efficacy	Total	13.6	21.4
	GP	7.1 (1.3-17.6)	9.0 (2.5-20.5)
	PN	7.4 (1.5-16.7)	12.4 (4.3-24.7)
Social support	Total	11.4	17.9
	GP	4.3 (0.4-13.1)	7.2 (1.7-17.3)
	PN	6.9 (1.3-15.9)	10.8 (3.5-22.2)
Age	Total	7.3	2.8
	GP	5.4 (1.1-15.4)	2.1 (0.2-8.6)
	PN	2.8 (0.2-10.7)	1.3 (0.1-7.1)
Disease severity	Total	6.4	7.5
	GP	8.4 (2.6-20.2)	7.2 (1.9-18.6)
	PN	1.3 (0.1-7.4)	1.9 (0.0-8.5)
Knowledge of disease	Total	3.2	6.8
	GP	1.6 (0.01-7.1)	2.9 (0.1-10.3)
	PN	1.8 (0.0-8.4)	3.8 (0.1-11.9)
Disease DM-II vs COPD	Total	0.5	2.6
	GP	0.1 (0.0-3.4)	0.8 (0.0-6.3)
	PN	0.5 (0.0-5.1)	1.7 (0.1-8.8)



7

Unravelling effectiveness of a nurse-led behaviour change intervention to enhance physical activity in patients at risk for cardiovascular disease: study protocol of a clustered-randomized controlled trial in primary care

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Submitted

Abstract

Background

Self-management interventions are considered effective in chronic disease patients, but trials have shown inconsistent results and it is unknown which patients benefit most. Adequate self-management requires behaviour change in both patients and healthcare providers. Therefore, the Activate intervention was developed focussing on behaviour change in both patients and nurses. The intervention aims for change in a single self-management behaviour, namely physical activity, in primary care patients at risk for cardiovascular disease (CVD). This study aims to unravel the effectiveness of the Activate intervention.

Methods

A two-armed, cluster randomized controlled trial will be conducted comparing the Activate intervention with care-as-usual in 30 general practices in the Netherlands, approximately 277 patients at risk for cardiovascular disease will participate. The Activate intervention is developed using the Behaviour Change Wheel (BCW), and consists of four nurses-led consultations provided in a 3-months period, integrating 17 behaviour change techniques (BCTs). The BCW was also applied to analyse what behaviour change is needed in nurses to deliver the intervention adequately. This resulted in a one-day training and coaching sessions (including 21 BCTs).

Primary outcome is physical activity, measured as number of minutes of moderate to vigorous physical activity and will be assessed with an accelerometer. Potential effect modifiers are age, BMI, level of education, social support, depression, patient-provider relationship and baseline amount of minutes of physical activity. Data will be collected at baseline, at 3 months and at 6 months follow up. A process evaluation will be conducted to evaluate the training of nurses, fidelity, dose and reach of the intervention, to identify barriers and facilitators for implementation and to assess participants' satisfaction.

Discussion:

The Activate intervention aims to increase physical activity in patients and to support nurses in delivering the intervention. BCTs are applied to change behaviours of the patient and the nurse. Evaluation of the effectiveness of the intervention, exploration of which patients benefit most, and evaluation of our theory-based training for primary care nurses will enhance understanding of what works in whom, which is essential for further implementation of self-management in clinical practice.

Background

Considering the rising number of patients with one or more chronic diseases, there is an urgent need for effective interventions to enhance self-management. Self-management interventions aim to support patients to actively participate and take responsibility to self-manage symptoms, treatment, physical and psychosocial consequences, behaviour and lifestyle changes in daily life ¹. Adequate self-management requires behaviour change in both patients and health care providers. Self-management interventions have become an important part of the care for patients with chronic disease as they have shown to positively affect health outcomes, including disease-specific outcomes, quality of life, self-management behaviour and cost effectiveness ²⁻⁷. However, a substantial proportion of patients does not comply or respond to these interventions, raising new questions regarding in whom these interventions work best ⁸. Trials included different groups of patients with varying characteristics, which may also contribute to this heterogeneity in effect size. Self-management interventions might be more or less effective in specific subgroups of patients. Patients characterized with e.g. low self-efficacy, lower health related quality of life, younger age, no depressive symptoms, low education level, low income, and lower baseline self-management capacity tend to benefit more from self-management interventions ⁹⁻¹¹. However, evidence is inconclusive and needs further research ¹². Furthermore, heterogeneity in trial designs, intervention components, follow-up time, outcome measures, scarcely measured and reported fidelity to study protocols may contribute to the heterogeneity in effectiveness of self-management ^{2-4,13}. Therefore, further research is essential to unravel effectiveness of self-management interventions and to explore in whom these interventions work best, and whether they can be delivered as intended. For this purpose we designed the Activate intervention in which we focus on a large heterogeneous subgroup of patients monitored in primary care, namely patients at risk for cardiovascular disease (CVD). Patients who are at risk for CVD have at least one major risk factor: high blood pressure, high cholesterol, diabetes mellitus type 2 (DM2) or a positive family history of CVD ¹⁴. Guidelines on CVD prevention recommend pharmacotherapy, and increasing patients' level of physical activity, healthy diet, reduction of alcohol consumption, and cessation of smoking ^{15,16}. The Activate intervention is targeting at increasing physical activity, which is considered to be one of the most relevant self-management components for patients at risk for CVD. Adequate physical activity is associated with a lower risk of developing diabetes, decreased mortality, blood pressure, obesity, cholesterol level, and CVD-related symptoms ¹⁷⁻²³. Patients are recommended to exercise at least 30 minutes of moderate activity a day for at least five days a week ²⁴. Yet, patients often fail to achieve this threshold, which emphasizes the need for changing their inactive behaviour ^{25,26}.

Achieving behaviour change is complex and requires skills and competences of both patients

and health care professionals. In routine consultations, behaviour change support is often brief and fragmented, and rarely includes recommendations on how to achieve behaviour change²⁷⁻²⁹. This underlines that health care providers also need to change their behaviour in order to adequately support patients in behaviour change. Nurses need to change their consultation style from the traditional patient education to teaching patients problem-solving skills and supporting them in changing their behaviour, goal setting and action planning³⁰⁻³². Unfortunately, training of health care providers does not always lead to sufficient improvement of their skills and competences and lacks sustainability of the acquired skills into their daily routine²⁸. Insufficient adoption of trained skills and competences might influence the ability to adhere to study protocols and dilute the effect of the intervention³³⁻³⁵. A promising approach for developing interventions to enhance behaviour change in patients and health care providers is the comprehensive Behavior Change Wheel (BCW)^{36,37}. The BCW incorporates 19 theoretical behaviour change frameworks and helps interventionists to choose specific Behaviour Change Techniques (BCTs)^{36,37}. BCTs can be regarded as active components of behaviour change and are recently defined in the BCT taxonomy v1 (BCTTv1) by Michie et al.³⁸. The Activate intervention is developed using the BCW. Specifying the BCTs is intended to unravel effectiveness of the intervention and to explore which patients benefit most. The primary objective of this study is to evaluate the effect of the Activate intervention on increasing physical activity in primary care patients at risk for CVD. Secondary objectives are to:

1. Evaluate the effect of the Activate intervention on patients' sedentary behaviour, self-efficacy, level of activation, and health status in primary care patients at risk for CVD.
2. Identify which patient-related characteristics modify change in physical activity levels.
3. Evaluate the training of nurses, fidelity to the study protocol, dose and reach of the Activate intervention, perceived barriers and facilitators for implementation, and satisfaction with the Activate intervention.

Methods/ Design

Design

We designed a two-armed, clustered randomized controlled trial to compare the Activate intervention with care as usual. Figure 1 shows a schematic overview of the trial design. To optimize reporting of this trial and to enhance validity, the CONSORT criteria are followed throughout this protocol³⁹.

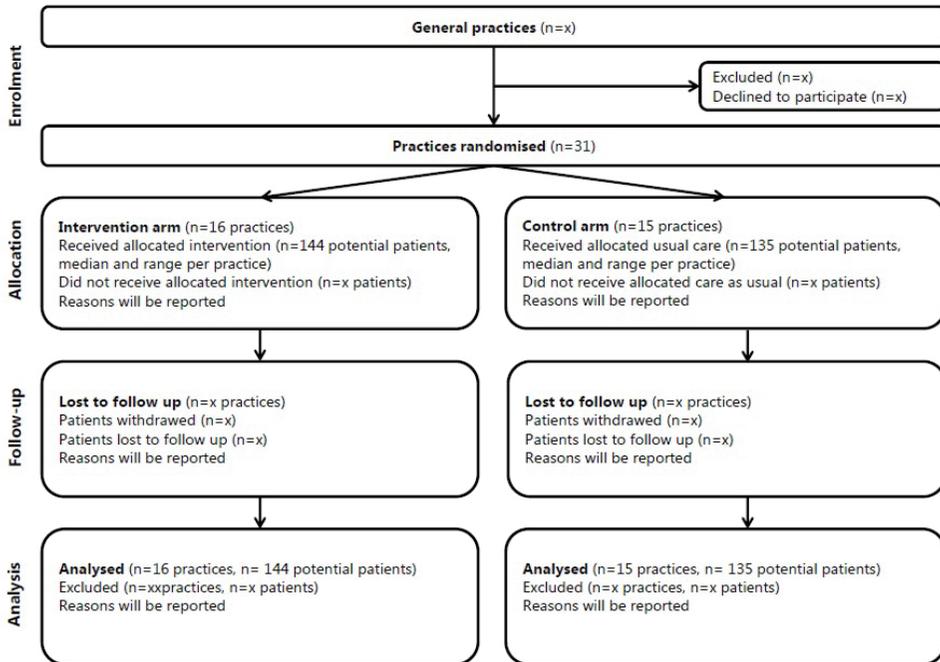


Figure 1. CONSORT diagram for Activate showing participants flow through each stage of the randomized trial

Participants

Patients will be recruited from general practices by primary care nurses in agreement with the general practitioner. The study population consists of adult patients at risk for CVD, who are supported by a primary care nurse working in a general practice.

Inclusion criteria

Eligible patients have at least one of the following risk factors as described in the Dutch guideline for cardiovascular risk management (CVRM)¹⁶:

–Aged 40-75

AND at least one of the following criteria:

- have a high blood pressure (≥ 140 mmHg) or are already treated for high blood pressure
- have a high total cholesterol (≥ 6.5 mmol/l) or already treated for high cholesterol
- have diabetes mellitus type 2 (DM2)
- have a positive family history of CVD

AND

Do not meet the Dutch Norm for Healthy Exercise ²⁴ according to the Short QUestionnaire to Asses Health (SQUASH)⁴⁰.

Exclusion criteria

Patients are excluded from the study if they are unable to give informed consent (e.g. due to cognitive impairment), are unable to speak, write and read Dutch, have contra-indications to increase their physical activity level (e.g. unstable angina pectoris, unstable heart failure, acute illness), have a terminal illness or have severe psychiatric illness or chronic disorder(s) that seriously influence the ability to improve their psychical activity level. Moreover, patients should not have participated in a program to increase their level of physical activity in the past 2 years.

Study procedures

Selection and recruitment

Recruitment will start via primary care nurses working in general practices located in the Netherlands. Nurses will be recruited by an invitational e-mail, by telephone and personal contact with primary care nurses, general practitioners and practice managers, until 30 general practices are enrolled. Each general practitioner selects as many candidate patients as needed to recruit 9-10 patients. Eligible patients receive an envelope by mail containing an invitational letter signed and dated by their attending nurse and general practitioner, study information, informed consent and a short self-assessment of patients' physical activity level using the SQUASH⁴⁰. Patients are asked to bring the letter, informed consent, and the filled out SQUASH to their next scheduled visit to the nurse. During the consultation the nurse will check whether patients are eligible and willing to enrol in the study.

Ethical considerations

The Activate trial is ethically approved by the Institutional Review Board of the University Medical Center Utrecht with protocol ID NL54286.041.15. Personal data will be coded and handled confidentially.

Informed consent

A modified informed consent to postponed information procedure is used⁴¹. With this procedure, a valid assessment of subjective outcomes can be obtained even when patients could not be blinded to the intervention⁴¹. Using the modified informed consent procedure in our trial, selection bias by attrition or drop-out can be reduced. Patients' preference for allocation to the treatment arm above care as usual might result in increased dropout in the control group, due to being dissatisfied or lack of interest⁴². At the end of the follow-up period patients will receive postponed information about randomization and allocation of their general practice.

Randomisation and blinding

Participating general practices will be randomly allocated to the intervention or control group after formalisation of participation. Randomisation at the level of the general practice allows evaluation of the intervention without contamination bias arising from diffusion of the intervention towards control patients. For comparability of both groups, minimisation will be used to balance geographical regions of the general practices. To safeguard allocation concealment, the randomisation procedure is supervised by an independent data manager and performed by web-based randomization software. Blinding the general practices and their nurses is not possible since nurses will perform the intervention. The investigators will be aware of the allocation, as they directly communicate with the general practices and nurses about the study and they are involved with the training of nurses. All patients will be informed about the assessment of level of physical activity. Patients will be blinded as a result of the postponed information procedure. Patients who are allocated to the intervention group will only be informed about the intervention. Patients allocated to the control group will only be informed about the data collection in the control group.

Intervention development

The Medical Research Council (MRC) framework was used as a guide for the development and evaluation of the Activate intervention^{43,44}.

The Behaviour Change Wheel (BCW) was used to systematically develop the Activate intervention. We applied the BCW twice. Firstly, we applied the BCW to understand what hinders and facilitates patients in changing their level of physical activity. Secondly, we applied the BCW to analyse what behaviour change is needed in nurses to deliver the Activate intervention adequately.

The BCW consists of three layers, see Figure 2. In the first layer we identified the source of the behaviour that could prove targets for the intervention (what needs to change) by conducting a COM-B (Capacity, Opportunity or Motivation influencing Behaviour) analysis. To expand on COM-B, the Theoretical Domains Framework (TDF) was used. However, the TDF is not a part of COM-B. In the second layer we used COM-B to generate a list

of intervention functions options. Intervention functions (e.g. education, persuasion) are broad categories of means by which an intervention can change behaviour. To determine which intervention functions to use we used the APEASE criteria (affordability, practicality, effectiveness and cost-effectiveness, acceptability, side-effects/safety and equity). The third layer of the BCW identifies seven types of policy (e.g. guidelines, social planning, legislation) that can be used to deliver the intervention functions^{36,37}. This layer was not applicable for us since the intervention is not being implemented on a broad scale, but studied in a small number of practices. Finally, the intervention functions were linked to the BCTs described in BCTTv1, and we selected BCTs considering the APEASE criteria and available evidence of their effectiveness in literature.

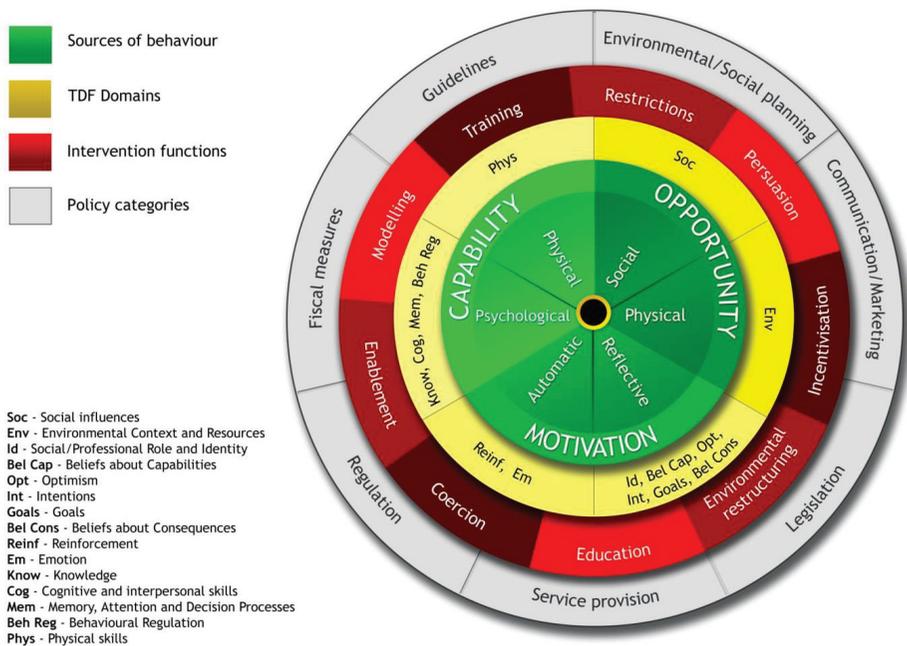


Figure 2. The Behaviour Change Wheel (BCW) and TDF Domains

Applying the BCW to enhance physical activity in patients

We conducted a review of qualitative studies to understand the behaviour and to identify what needs to change, using COM-B and TDF. We identified patients’ perceived barriers and facilitators in increasing their level of physical activity until saturation was achieved. In the second layer of the BCW, we selected intervention functions likely to be most effective for the target behaviour to occur (Annex 1).

Subsequently, the intervention functions were directly linked to a selection of appropriate and effective BCTs, resulting in 17 BCTs (Table 1). This selection of BCTs is guided and peer-reviewed by experts in behaviour change. Each BCT is thoroughly designated for

application in the Activate intervention following the definition of each BCT as described in the BCTTv1 taxonomy³⁸, resulting in four different consultations to enhance physical activity in the patients' home environment. During this process two focus groups were held with primary care nurses to apply the APEASE criteria and to validate the intervention for feasibility in practice.

Table 1. Selected BCTs for the Active intervention and division of BCTs over consultations

Selected BCTs from BCTTv1	BCTs divided over four consultations			
	1	2	3	4
1. Goal setting (behaviour)	x	x	x	x
2. Problem solving (Includes barrier identification and relapse prevention)	x	x	x	x
3. Goal setting (outcome)	x			
4. Action planning		x	x	x
5. Review behavioural goal(s)		x	x	x
6. Commitment		x	x	x
7. Feedback on behaviour	x	x	x	x
8. Self-monitoring of behaviour	x	x	x	x
9. Social support (unspecified)		x	x	x
10. Social support (practical)		x	x	x
11. Information about health consequences	x	x		
12. Prompt/ cues	x	x	x	x
13. Habit formation			x	x
14. Graded tasks		x	x	x
15. Restructuring the physical environment	x	x	x	x
16. Restructuring the social environment	x	x	x	x
17. Focus on past success		x	x	x

Abbreviation: BCTTv1: Behaviour Change Technique Taxonomy v1, BCT: Behaviour Change Technique

Applying the BCW to deliver the Activate intervention by primary care nurses

Subsequently to the development of the Activate intervention we applied the BCW in nurses. In the first layer of the BCW, we explored qualitative literature and held a focus group with primary care nurses to identify what nurses need to change to deliver the intervention. Prior to the focus group nurses were asked to give their opinion on a 4-point likert scale (1=totally disagree, 4= totally agree) on the APEASE criteria regarding the 17 BCTs in daily practice and to reflect on their capability, opportunity and motivation to apply these BCTs. Results of the literature and focus group showed that all components of COM-B need to be

targeted to adequately deliver the BCTs integrated in the Activate intervention (Annex 2). In the second layer of the BCW we selected intervention functions (Annex 2), and directly linked these to appropriate and effective BCTs (Table 2). This resulted in a selection of 21 BCTs. Each BCT is thoroughly designated for appliance in a standardized training for nurses to equip them to deliver the intervention as intended. This process is peer-reviewed by experts and checked for face validity by four primary care nurses during a second focus group.

The Activate intervention

The Activate intervention is developed for patients at risk for CVD. The intervention is standardised in four nurse-led consultations to enhance physical activity: in the first week, after 2, 6 and 12 weeks. Although the BCTs are systematically applied in the intervention, the content will be adapted to the individual patient and his unique circumstances, by goal setting, action planning, feedback, etc. The duration of the first consultation is 30 minutes and the following consultations last 20 minutes. During the first consultation patients will receive a workbook containing information about the study, useful websites and apps, tips and tricks, activity logs and action plans. In the first consultation the nurses will discuss the patients' CVD risk profile, the consequences of a sedentary and active lifestyle and self-assessment of their activity level in order to raise awareness to improve the level of physical activity of the patient. Together the patient and nurse formulate an overall outcome goal and an exercise goal considering physical activity in minutes per day. In order to raise awareness of self-monitoring and how to self-monitor, the patient is asked to self-monitor his physical activity during the next two weeks by using an accelerometer and a paper activity log which provides feedback on patients' level of goal attainment. Additionally, the patient is asked to identify facilitators to goal attainment. During the second consultation, the nurse rehearses the information about the consequences of an active lifestyle, reviews the goal attainment using the activity log kept by the patient, and discusses the identified facilitators. If applicable, the physical activity goal is re-formulated. A specific action plan to attain the level of physical activity as formulated in their goal is set up. The patient is supported in finding ways to use facilitators for physical activity, is asked to self-monitor his activities during the next weeks, in order to attain the set physical activity goal, and to identify possible barriers to goal attainment. In the third consultation the nurse will give feedback on the reached level of goal attainment during the past weeks, using the log kept by the patient. If applicable, the activity goal and specific action plan are adjusted. Furthermore, the nurse will discuss how to prevent relapse into an inactive lifestyle (old habits) by discussing the barriers for relapse and will discuss how to build new habits to keep the active lifestyle. The patient is asked to self-monitor his activity level during the next weeks, in order to attain the set physical activity goal and to identify possible barriers and facilitators to goal attainment. In the last consultation the nurse will give feedback on the reached level of goal attainment

during the past six weeks, using the results of self-monitoring and activity log kept by the patient and identified facilitators. Furthermore, the nurse will rehearse how to prevent relapse into old habits and the formation of new activity habits.

Training of primary care nurses

The results of the BCW of nurses' behaviour led to the development of a standardized training. In collaboration with an educationist and a health psychologist we integrated the 21 BCTs in a comprehensive training program (see Table 2). Prior to inclusion of patients, nurses allocated to the intervention arm will receive a one-day interactive, educational, face-to-face and accredited training in a small group outside the general practice, led by a health psychologist. To prepare themselves for the training, nurses will be asked to watch instruction videos of the study procedures and a video of background information on the importance of physical activity in patients at risk for CVD provided by a physiotherapist. At the start of the one-day training nurses will be asked to fill out a self-assessment and discuss their results in a group discussion. This self-assessment is specifically developed for this study to provide insight in their competences in applying the 17 BCTs integrated in the Activate intervention and their outcome expectancy on these BCTs. The key focus of the one-day training is learning how to address the BCTs in each consultation. Furthermore, the one-day training entails an explanation of the intervention and its timeline, and information about the health consequences of physical activity. The training will contain a combination of didactic presentations, short videos of how to apply the BCTs in each of the consultations, small group discussions and role-plays. Furthermore, nurses receive two individual coaching sessions by the health psychologist in which the trained skills in applying the BCTs are rehearsed and optimized. Prior to each coaching session nurses will be asked to audiotape one of their consultations of the Activate study in their practice, which will be discussed during the coaching session. The nurses will be provided with several resources, which they can use during their consultations. They will have a workbook for each patient in which charts (what to do when) and example sentences are given to help them to deliver the BCTs effectively. Additionally to the individual coaching sessions, nurses will be asked to watch the videos of how to apply the BCTs in the intervention to reinforce their skills and competences in delivering the Activate intervention. The division of selected BCTs over the different components of the training is shown in Table 4.

Feasibility and piloting

The training for nurses was pilot-tested in a small feasibility study. Two primary care nurses completed the training and one patient at risk for CVD completed the consultations to evaluate whether the consultations were feasible in time and to ensure the intervention matches with patients' needs and can be incorporated in daily life. Their experiences, barriers, strengths, limitations and time investments were

evaluated. The nurses indicated that the training adequately equipped them to deliver the intervention. They suggested minor adaptations, namely broader inclusion age of patients (40-75), easier interpretation of level of adherence to the Dutch Norm for Healthy Exercise according to the SQUASH and clear instructions on how to recruit and include patients. Time spent on the consultation was acceptable and according to the protocol. The patient was satisfied with the intervention and suggested minor adaptations in the lay-out of the activity log.

Table 2. Division of selected BCTs over the different components of the training of practice nurses

Selected BCTs from BCTTv1		BCTs divided over components training			
		Preparation	1 day training	Coaching sessions	Available resources
1.	Information about health consequences	x	x		x
2.	Information about social and environmental consequences	x	x		x
3.	Prompts/cues		x		x
4.	Feedback on the behaviour		x	x	
5.	Information about other's approval		x	x	
6.	Credible source	x	x	x	x
7.	Focus on past success		x	x	
8.	Verbal persuasion about capability		x	x	
9.	Reward		x	x	
10.	Monitoring of behaviour by others without feedback		x	x	
11.	Monitoring outcome of behaviour by others without feedback		x	x	
12.	Instruction on how to perform the behaviour	x	x	x	x
13.	Demonstration of the behaviour		x	x	x
14.	Behavioural practice/rehearsal		x	x	x
15.	Habit formation		x	x	x
16.	Adding objects to the environment		x	x	x
17.	Restructuring the physical environment		x	x	x
18.	Social support (unspecified)		x	x	
19.	Social support (practical)		x	x	
20.	Problem-solving		x	x	x
21.	Self-monitoring of behaviour		x	x	

Abbreviation: BCTTv1: Behaviour Change Technique Taxonomy v1, BCT: Behaviour Change Technique

Care as usual

Patients in the control arm will receive care as usual, according to the national healthcare standard for patients at risk for CVD ¹⁶, during regular consultations with their nurse and will not receive additional consultations, beyond standard of care, to increase their physical activity level. Patients at risk for CVD have at least one consultation per year with the nurse, however, this frequency can be extended when considered necessary (e.g. in case of medication change). Patients with DM2 have at least four consultations a year with the nurse. In order to keep the nurses in the control arm motivated, the one-day training will be offered to them at the end of the study.

Data collection

To assess the characteristics of the nurses participating in the study, a short questionnaire will be sent to nurses. To assess whether patients are eligible for improving their level of physical activity, patients are asked to fill out a short self-assessment using the SQUASH prior to consenting to the study. Nurses will interpret the filled out SQUASH using clear guidelines in order to see if a patient fits the inclusion criteria regarding the insufficient level of physical activity.

After enrolment, patient data will be collected at baseline (T0), after 3 months (T1) and after 6 months (T2) by an accelerometer, questionnaires and chart review, see Table 3. At time point T0 the nurses will distribute the questionnaires and accelerometer after enrolment during their regular scheduled visit. On time points T1 and T2 the research team will distribute the questionnaires and accelerometers. To enhance response rates, the research team will contact each collaborating general practice regularly. Nurses and patients can easily contact the research team for remarks and questions.

Table 3. Measurements and time points

Measurements	Data collection method	Time points		
		T0	T1	T2
Characteristics of patients				
Age (years)	Questionnaire	x		
Gender (no)	Questionnaire	x		
Employment status (n)	Questionnaire	x		
Living alone/ with others (n)	Questionnaire	x		
Years since diagnose (years)	Questionnaire	x		
Level of physical activity	Questionnaire (SQUASH)	x		
Smoking status	Questionnaire	x		
Alcohol consumption	Questionnaire	x		
Healthy food intake	Questionnaire	x		
BMI	Chart	x		
Blood pressure	Chart	x		
Cholesterol levels	Chart	x		
HbA1c (DM2 only)	Chart	x		
Level of education (n)	Questionnaire	x		
Health literacy	Questionnaire (HLS-EU-Q)	x		
Social support	Questionnaire (MSPSS)	x		
Depression	Questionnaire (HADS)	x		
Patient-provider relationship	Questionnaire (CAT)	x	x	x
Diagnosis of DM2, hypertension, hypercholesterolemia	Chart	x		
Medication for DM2	Chart	x		
Medication for high blood pressure	Chart	x		
Medication for high cholesterol levels	Chart	x		
Characteristics of primary care nurses				
Age (years)	Questionnaire	x		
Sex (male, female)	Questionnaire	x		
Achieved self-management training	Questionnaire	x		
Level of nursing education	Questionnaire	x		
Amount of working years	Questionnaire	x		
Amount of working years in field of CVRM	Questionnaire	x		
Geographical area of the general practice	Questionnaire	x		
Primary outcome				
Level of physical activity	Accelerometer	x	x	x
Secondary outcomes				
Sedentary behaviour	Accelerometer	x	x	x
Self-efficacy for physical activity	Questionnaire (ESS)	x	x	x
Patient activation	Questionnaire (PAM-13)	x	x	x
Health status	Questionnaire (EQ-5D)	x		x
Process evaluation	Questionnaire, focus groups		x	x

Abbreviations: SQUASH: Short QUestionnaire to Asses Health, HLS-EU-Q: European Health Literacy Project questionnaire, MSPSS: Multidimensional Scale of Perceived Social Support, HADS: Hospital Anxiety and Depression Scale, CAT: Communication Assessment Tool, CVRM: CardioVascular Risk Management, ESS: Exercise Self-efficacy Scale, PAM-13: Patient Activation Measure, DM2: diabetes mellitus type 2, BMI: Body Mass Index, HbA1c: glycated hemoglobin, T0: baseline, T1: after 3 months, T2: after 6 months

Outcome measures

Primary outcome

The primary outcome is physical activity, objectively measured as the number of minutes of physical activity in the moderate to vigorous category. This will be assessed with the Personal Activity Monitor (PAM AM300)⁴⁵. The PAM is a small valid and reliable tri-axial accelerometer, which can be easily worn on the hip. Additionally, patients will be asked to write down on a paper log the amount of minutes they are swimming, cycling or doing strength training since the accelerometer cannot measure these activities accurately. The number of minutes of physical activity in the moderate (3-6 METabolic equivalent (METS)) and vigorous categories (≥ 6 METS) at 6 months of follow up will be considered as primary outcome measure. Patients will be asked to wear the accelerometer during 7 consecutive days for 12 hours a day at baseline (T0), 3 months of follow up (T1) and at 6 months of follow up (T2). For a valid measurement the accelerometer has to be worn for at least 4 weekdays and 1 weekend day for 8 hours. The outcome is the average minutes of moderate to vigorous activity of all the valid days. With the Activate intervention a mean difference in minutes of 20% of at least moderate level of physical activity from baseline is considered to be clinically relevant and reasonable to achieve within 3 months of intervention.

Secondary outcomes

The secondary outcomes of this trial are:

1. Sedentary behaviour using the accelerometer measuring the amount of minutes in the sedentary category ($< 1,8$ METS)
2. Self-efficacy for physical activity using the Exercise Self-efficacy Scale (ESS)⁴⁶⁻⁴⁸
3. Patient activation using the Patient Activation Measure (PAM-13)^{49,50}
4. Health status using the EQ-5D⁵¹

Potential effect modifiers to investigate which patient characteristics modify change in physical activity level include age, depression using the Hospital Anxiety and Depression Scale (HADS)^{52,53}, BMI, level of education, social support using Multidimensional Scale of Perceived Social Support (MSPSS)⁵⁴, patient-provider relationship using the Communication Assessment Tool (CAT)⁵⁵ and baseline amount of minutes of moderate to vigorous level of physical activity using the PAM AM300.

Process evaluation

A mixed method process evaluation will be performed at the end of the study. To evaluate treatment fidelity^{34,56} and dose⁴⁴ of the delivered intervention, nurses allocated to the study arm will randomly audiotape one consultation of each of the four consultations. The audiotapes will be coded using a specifically for this study developed coding tool, existing of the content of each of the four consultations and the Behaviour Change

Counselling Index (BECCI) ⁵⁷. Additionally, nurses will be instructed to self-report on the presence of the patient and the discussed content during a consultation, the time needed per consultation, and reasons for patients' drop-out. To evaluate the nurses' perception of their skills and competences in applying the BCTs integrated in the Activate intervention, nurses will be asked to fill out the specifically for this study developed self-assessment at the start of the training, after the training, during the intervention period, and at the end of the study. At the end of the study, nurses in the intervention arm will be invited to an interview to discuss their perceptions of determinants of success and failure of the intervention. This includes evaluation on the methodological process, barriers and facilitators of the implementation, experiences of applying the BCTs, the training program, motivation of nurses and patients and the perceived effect of the intervention. Descriptive data about the reach of the intervention will be collected in order to identify existing socio-demographic biases in who received the intervention and who dropped-out the intervention. To evaluate patients' experiences, barriers and facilitators and satisfaction with the intervention, patients in the intervention group will be asked additional questions in the T1 questionnaire and a sample of patients will be invited to an interview at the end of the study.

Additional parameters

Patients' socio-demographic characteristics, including gender, employment status, living alone/ with others, years since diagnose, smoking status, alcohol consumption and healthy food intake will be collected by questionnaires at baseline. Blood pressure, cholesterol levels, HbA1c (DM2 only) and medication use will be extracted from the patients' charts by baseline. Characteristics from PNs, including age, level of nursing education, years of working experience as a primary care nurse, amount of working years in the field of CVRM, achieved self-management training and geographical area of the general practice will also be collected by baseline.

Statistical analyses

Effectiveness of the Activate intervention

Data will be analysed primarily according to the intention-to-treat and secondly according to per protocol principles. To examine the effect of the Activate intervention between the arms, a multilevel analysis will be performed (3-levels; time, participant, general practice). The continuous outcome data will be quantified by mean, SD, and 95% confidence intervals (CI) using linear mixed effects models. For the binominal outcome data risk ratios, and 95% CI will be estimated using Generalised Estimating Equations (GEE), using a log-link function. In case of non-convergence of a model, odds ratios will be estimated using a logistic mixed effects model. All mixed effect models include a random intercept for changes over time and between practices. An interaction term will be added for time and study-arm. Missing data will be handled according to the questionnaires' rules of missing data. Missing

outcome data will not be imputed since multilevel analysis is a flexible method for dealing with missing outcome data⁵⁸.

Potential effect modifiers

To examine which patient characteristics modify effectiveness of the intervention as reflected by increased physical activity level, subgroup analyses with pre-specified patient characteristics will be performed. These characteristics include age, BMI, level of education, social support, depression, patient-provider relationship, and baseline amount of minutes of physical activity. To identify potential effect modification, we will use GEE for each of these patient characteristics separately. The independent variables in the models will be the patient characteristic, random intercept, interaction term and patient level. Effect modification will be considered significant if the interaction term shows a level of significance of <0.05 .

All quantitative analyses will be performed in R for Windows V.2.15.3 (R Development Core Team, Released 2013, Vienna, Austria: R Foundation for Statistical Computing).

Process evaluation

Quantitative data will be analysed using descriptive statistics. The data of the audio recordings will be independently analysed by 2 researchers using the for this study developed coding tool to determine the fidelity and dose of the consultations.

The interviews with nurses and patients to assess their experiences with the intervention will be audiotaped and transcribed. These transcriptions will be analysed and qualitatively described.

Sample size calculation

The present trial is powered to detect a mean difference between the intervention arm and control arm of 20% in minutes of at least moderate level of physical activity. Based on the results of the It's Life trial⁵⁹ the mean level of physical activity in participants is 38 minutes (SD 18.1). The It's life trial is a three-armed trial performed in primary care in the Netherlands in patients with COPD and DM2 in which the researchers aimed to increase physical activity with a self-management support program and with the It's Life tool (a monitoring and feedback tool). This study found an increase in physical activity of 27% but only in the counselling and It's life tool group. We consider an increase in physical activity of 20% as clinically relevant. Taking a power of 80% and a significance level of 5% into account requires 89 patients per arm. Assuming an intra-cluster correlation of 0.05 and a cluster size of 8 patients per general practice requires 30-31 participating practices⁵⁸. Allowing a drop-out rate in patients of 15%, we aim to recruit patients in total and 9-10 patients per general practice.

Discussion

Despite the growing evidence for their effectiveness, so far self-management interventions show small effects on health outcomes. The effectiveness of interventions is ambiguous and the question who benefits most from these interventions is still unanswered. With the Activate study we expect to contribute to unravel effectiveness of self-management interventions and explore which subgroup of patients benefits most. Effectiveness of this intervention and understanding of which patients benefit from the intervention may lead to a broader application of this intervention in supporting patients to enhance behaviour change in other self-management components, e.g. dietary intake, alcohol use, medication adherence and smoking cessation. The Activate intervention was comprehensively developed using the BCW and was applied to the behaviour of both patients and nurses. Since the role of a competent health care provider is essential in the delivery and fidelity of self-management interventions^{33,34,60,61}, we aimed to equip nurses with a training that supports nurses to increase their skills and competences to adequately deliver the intervention. This study has several strengths. We performed a detailed analysis of the behaviour of both patients and nurses. Subsequently, BCTs were selected and described, which will enhance reproducibility of the intervention. Furthermore, this clustered RCT is being conducted across several general practices in different geographical areas in the Netherlands with patients' own primary care nurse, rather than trained researchers delivering the intervention. This strengthens the generalizability and relevance of the findings from this trial for primary care. Another methodological strength is the use of the informed consent to postponed information procedure, which reduces selection bias by attrition or drop-out of patients. In our study, the control group might be dissatisfied not receiving the intervention, which increases the risk of biased results. Changes in outcome may only be affected due to a demoralized and perhaps less motivated control group. A methodological challenge is the objective measurement of the primary outcome by accelerometry. Since cycling, strength training, and swimming are activities that cannot be measured with the accelerometer, we will ask patients to self-report on these activities. However, these self-reported data will not be considered as primary outcome. Furthermore, wearing the accelerometer might stimulate patients to be more active, however these effects apply for patients in both intervention and control arm. This might reduce the effect of the intervention. The use of the self-reported SQUASH for inclusion of patients will possibly lead to over-estimation of their level of physical activity accounting less eligible patients for inclusion⁶². The training and consultations were pilot-tested in only two primary care nurses and one patient, which limits the insight in the barriers and facilitators of performing the intervention.

Conclusion

In conclusion, the effectiveness of self-management interventions needs to be further unravelled to better target effective components of self-management interventions to increase self-management behaviours and health outcomes. The Activate intervention aims to increase physical activity in patients by supporting nurses in delivering the intervention. We will thoroughly evaluate the effectiveness of our intervention on physical activity level, explore which patients benefit most, and evaluate the training for primary care nurses in order to contribute to further unravelling the effectiveness of self-management interventions and implementation of self-management in clinical practice.

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Annex 1. Results of the behavioural analysis in patients to increase the level of psychical activity using the BCW

COM-B	TDF	What needs to happen for patients to increase their level of physical activity	Intervention functions
Physical capability	Physical skills	Have the skills and physical capability to walk ¹⁻⁹	Training, enablement
Psychological capability	Knowledge	Have the knowledge and understanding of how to increase their level of physical activity, plan (why and how to do it) to reduce misperceptions and increase sense of urgency ⁹⁻¹⁴	Education
	Cognitive and interpersonal skills	NA	NA
	Memory, attention and decision processes	Notice and remember to be physical active, make everyday decisions to exercise according to an action plan ⁴	Training environmental restructuring enablement
	Behavioral regulation	Develop skills of goal setting, self-monitoring, adherence to wearing an accelerometer, action planning ¹² Need to change well-established habits ⁷	Education training enablement
Physical opportunity	Environmental context and resources	Have time to exercise ^{4,7,9,12,14} Have good weather or good shoes and clothes for all weather types ^{3-5,14,15} Have alternatives to deal with bad weather, neighbour insecurities, transport problems. ¹⁴ Improve easy access to affordable and stimulating facilities (at home or in their neighbourhood) tailored to the patients' needs and preferences ^{1,5,9,14,16}	Training restriction environmental restructuring (enablement)
Social opportunity	Social influences	Have positive support from family, friends, caregivers, fellow patients (e.g. have a buddy to exercise with or a buddy that supports exercise) ^{5,7,9,11,17,18} Have a collaborative relationship/ communication with caregiver ^{6,18,19} Have a competent caregiver (knowledge, clear guidance and stimulation, supervision, tailored advice, addressing importance of physical activity) ^{1,4} Overcome culture and language barriers ²⁰ Have role models ²¹ Have triggers to prompt (rewards, telephone, supervision, mail) ^{2,3,13,14}	Environmental restructuring restriction enablement modelling

Annex 1. continued

Reflective motivation	Professional/ social role and identity	Have a competent caregiver (knowledge, clear guidance and stimulation, supervision, tailored advice, addressing importance of physical activity) ^{1,4,6}	Modelling education persuasion
	Beliefs about capabilities	Overcome personal struggles (anxiety in unfamiliar surrounds, negative, or depressive emotions, body images) ^{6,14,17}	Education persuasion
	Optimism	Cope with negative attitudes and experiences ¹⁵ Believe that exercising will get easier after a while	Education persuasion (enablement modelling)
	Beliefs about consequences	Believe that exercise is good, and has positive influences on their cardiovascular risk Believe that excising will make you feel better after a while ¹⁷	Education persuasion modeling
	Intentions	Intend to exercise and become more active Feel they want to change physical activity level ^{5,12}	Education persuasion incentivisation modeling coercion
	Goals	Set achievable and personal goals ⁴	Education persuasion incentivisation modeling enablement
Automatic motivation	Reinforcement	Have positive prompts and prompts in environment Have routines and habits for daily exercising Change well-established habits ^{7,11}	Training, environmental restructuring incentivisation coercion
	Emotion	Feel they want to change physical activity level ^{3,5,7,11,14,15}	Persuasion incentivisation coercion, modelling enablement
Abbreviations: BCW: Behaviour Change Wheel, COM-B: Capability, Opportunity, Motivation, Behaviour, TDF: Theoretical Domains Framework, NA: not applicable			

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Annex 2. Results of the behavioural analysis in primary care nurses to deliver the intervention using the BCW

COM-B	TDF	What needs to happen for primary care nurses to adequately deliver the intervention	Intervention functions
Physical capability	Physical skills	<ul style="list-style-type: none"> – Have the skills and rehearse BCTs #¹ – Let the patient participate; not filling in for the patient #¹ – Have effective communication tools and skills in counselling and shared decision-making #² – More education and exercise to know how to develop a concrete and structured action plan #³ 	Training, enablement
Psychological capability	Knowledge	<ul style="list-style-type: none"> – Have the knowledge to perform the BCTs # – Have the knowledge to activate a patient # – Reinforce performing the BCTs # – Give education about activating patients and tips what to do when patients complain of physical pain # 	Education
	Cognitive and interpersonal skills	NA	
	Memory, attention and decision processes	<ul style="list-style-type: none"> – Having a clear integral form to guide nurses thorough the steps for goal setting and action planning will help and encourage them to do it # – Prioritize performing BCTs on physical activity and not let other things get in the way #¹ 	Training, environmental restructuring, enablement
	Behavioral regulation	NA	
Physical opportunity	Environmental context and resources	<ul style="list-style-type: none"> – Have more time to perform the BCTs #³ – Have the tools to perform the BCTs (to self-monitor, overview of physical activity options in the area, information brochures websites, apps, etc) # – Not hesitate to use new tools in practice¹ 	Training, restriction, environmental restructuring, enablement
Social opportunity	Social influences	<ul style="list-style-type: none"> – Have support to participate from general practice (e.g. time and education opportunities) # – Self-management is encouraged throughout the entire general practice # 	Environmental restructuring, enablement

Annex 2. continued

Reflective motivation	Professional/ social role and identity	– Feel that it is part of their role [#] – Understanding that activating a patient is part of the nurses' role and not necessarily of a physiotherapist ³	Modelling, education, persuasion
	Beliefs about capabilities	– Feel confident that they can do it even the patient is not motivated [#] – Patients often have excuses, lack of motivation or have physical complaints, which makes it difficult for the nurse [#]	Education, persuasion, modelling
	Optimism	– Achieving behaviour change is seen as difficult or even as impossible ¹	Education, persuasion, modelling
	Beliefs about consequences	NA	
	Intentions	NA	
	Goals	NA	
Automatic motivation	Reinforcement	– Feel that they are making a difference [#]	Training, persuasion, incentivisation
	Emotion	NA	
[#] Results from focus group with primary care nurses Abbreviations: BCW: Behaviour Change Wheel, COM-B: Capability, Opportunity, Motivation, Behaviour, TDF: Theoretical Domains Framework, BCT: Behaviour Change Technique, NA: not applicable			

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8

General Discussion

In this thesis we aimed to explore how self-management support is perceived and performed in clinical practice and to study various aspects of tailoring self-management support. When we started this project self-management was already a trending topic, however, it was obvious from many reviews that self-management interventions are not effective in every chronic disease patient and that broad implementation of self-management in routine clinical practice is challenging. Therefore, we aimed at gaining more knowledge on perceptions of care providers on the concept of self-management, how self-management support is tailored in clinical practice, what patient factors are involved in the tailoring process, and which competences nurses need to tailor self-management support. In this final chapter we will reflect on the main conclusions from our studies and provide recommendations for clinical practice and future research.

Reflections on the concept of self-management and perceptions of professionals

Conclusion 1: We are lost in translation regarding the terminology of self-management and related concepts, which leads to differences in the provision of self-management support.

We found that nurses substantially differ in their perceptions of self-management, which leads to different ways of providing self-management support (Ch. 4). Some consider self-management as a shift in responsibility from professional to patient whereas others see self-management as a broader concept of optimizing patient skills and changing lifestyle behaviours. The way in which self-management support is delivered also varies; from actively trying to support the patient in increasing his self-management capacities and skills to more passively awaiting patients to take up a more active role in their personal health care management. We also learned that because chronic care today is strictly protocolled and time consuming, care providers find limited time for self-management. Unclear perceptions and ill-defined aims with self-management also contribute to the fact that care providers do not prioritize self-management. In line with Bourbeau & van der Palen, we suggest that the pivotal objective of self-management support should be to change patients' behaviour (medically and non-medically related) and to teach them new skills for better disease control and patient outcomes¹.

In the literature, various definitions and concepts of self-management are used interchangeably; self-care, self-management and disease-management. For instance, in heart failure literature self-care is the dominant term. To add to the confusion self-management is used to describe how a patient is performing self-management, as a patient characteristic, at the same time it is used to describe a professional's way of working. The chronic care model identified self-management as one (out of six) key element to achieve better chronic disease management². Throughout all our research we used a definition

of self-management that we regarded as most comprehensive, and which focusses on the patient, namely the definition of Barlow et al.: “self-management is the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life”³.

There are many other concepts *linked* to self-management and self-management support, which sometimes add further to the confusion in terminology. These concepts can be supportive in implementing self-management. *Patient-centred care* means an approach whereby the provider tries to enter the patients’ world in order to see illness through the eyes of a patient. The provider is guided by the patients’ knowledge, experience, needs and preference⁴. As Johnston and colleagues state; self-management support is a complex and patient-centred concept⁵. *Patient empowerment* is defined as helping patients discover and develop the inherent capacity to be responsible for one’s own life. It can support patients in becoming more confident to self-manage their illness. *Personalized care planning* is a collaborative process in which patients and clinicians identify and discuss problems and develop a plan for tackling these by jointly setting goals and actions for managing the patient’s condition⁶. This is often seen as an important part of effective self-management support, as is shared *decision making*. This is an approach whereby health professionals and patients work together to understand problems, define preferred outcomes and set goals, share information and reach mutual agreement on the best health intervention for the individual patient⁷. To become good self-managers patients have to agree with adopting new skills and the need to change behaviour. *Motivational interviewing* is an in-depth approach to decision making intended to help patients come to their own decisions by exploring their uncertainties⁸. This can be instrumental in the success of self-management support.

All these emerging concepts and definitions that were introduced in the past years, led to substantial confusion, both in the scientific, clinical and public domain. Care providers have their own perceptions of these concepts and use them in their practice the way they consider best. We regard these concepts as part of the paradigm shift in healthcare in which we move from professional driven care towards patient-centred care. This calls for an entire new perspective on health care provision, with changing roles for patients and care providers. The various concepts that were discussed can successfully support this development.

Recommendation for clinical practice:

- Clinical guidelines should use a uniform definition of self-management, and operationalize this definition to set clear goals, explain which self-management support components are useful and clarify what self-management support is expected from which care provider. Also, the aims of providing self-management support should be clear.

Recommendations for future research:

- In future research clear definitions and aims of self-management (support) should be used.
- Researchers on themes such as self-management, shared decision making, behaviour change, and motivational interviewing should work collaboratively towards implementing these concepts in clinical practice and strive for consensus in terminology. They should also use clear ways of measuring the concepts to enable full understanding of the interactions and to facilitate implementation.

Reflections on tailoring of self-management

Conclusion 2: Self-management support needs to be tailored to the individual. Patient assessment is the key driver of tailoring; however there is wide variation in the way and extent this assessment is currently done. The quality of the assessment determines if and how self-management support is tailored in clinical practice.

In the current way of thinking about healthcare and patient-centred care it is obvious that self-management support needs to be tailored to the individual. Patients need to perform self-management activities in their daily lives with respect to their circumstances. It needs to be emphasized that since every person and his or her context is unique, self-management needs to be adapted to the individual. From our research, we conclude that tailoring definitely has a place in current practice, however, the way in which patients are assessed seems to determine if and how health care provision is individualized. Assessments and tailoring are sometimes more subconscious rather than intentional actions. Therefore, various ways of tailoring exist in clinical practice. Despite the differences in patient assessment, care providers seem to have pre-set expectations of how successful self-management support will be in individual patients, and they often adjust their support accordingly. Some care providers intentionally individualize their self-management support in all patients while others merely select patients in whom they expect self-management support to be successful. This makes that patients considered unsuitable for self-management do not get the necessary support (Ch. 4&6). Choices in tailoring health

care in interventions are commonly based on content (Ch. 3&4). For instance, if a patient is eating healthy and adhering well to the medication, these self-management areas are not addressed, and the focus in self-management is on areas where there is something to gain.

In a tailored approach self-management support is customized, based on the unique needs and characteristics of that patient, in order to improve treatment outcomes. Customization refers to the personalized action plan with variations in content (topics), use of behaviour change techniques, mode of delivery (face-to-face, e-health, supportive materials) and dose (duration or frequency) of contact moments⁹. When a subgroup, based on a specific characteristic, is used to develop a single intervention/program for this defined subpopulation this is called targeting (e.g. a cultural subpopulation or patients with health literacy).¹⁰ To be able to tailor or to target self-management support more knowledge is needed on what patient factors require customization. A recent practical systematic review by Taylor and colleagues about interventions supporting self-management for people with long-term conditions found that effective self-management support should be tailored to the individual, their culture and beliefs, the specific disease and the position on the disease trajectory¹¹.

Conclusion 3: Many patient factors play a role in an individual's self-management capacity and activation for self-management. In decision-making towards self-management support care providers consider motivation as the most important factor.

Many factors are associated with self-management capacity: in chapter 2 we identified 9 explaining variables that explained only 16% of the variance. These factors are associated with the current activation level for self-management and therefore we do not know whether these factors will have an effect on how patients respond to self-management support. From subgroup analyses in heart failure self-management interventions (Ch. 3) we learned that some factors are associated with a positive change following a self-management intervention (low: income, literacy, education, baseline self-management capacity), others were associated with a negative change (depression and cognitive dysfunction), and some factors did not have any association with change but only with current self-management status (i.e. age, gender, ethnicity, disease severity, number of comorbidities). In the subsequent chapters we found that many more factors play a role in the degree to which patients are engaged in self-management from a provider's perspective (Ch. 4,5 &6), and from a patient's perspective (Ch. 7). All the factors are summarized in Table 1.

From a care providers perspective motivation seemed to be the most important patient factor for success of self-management support. Increasing motivation is difficult for

care providers; they even tend to abandon self-management support in unmotivated patients, who are therefore less likely to receive self-management support (Ch.4&6). Schulman-Green and colleagues also recognized that from a patient's perspective many factors interact with each other and affect the individual's ability or motivation for self-management¹².

Table 1. Patient factors that can play a role in self-management (derived from the different chapters in this thesis)

Age, BMI, educational level, financial situation, social support, living situation, private situation, self-efficacy, motivation, cultural aspects, disease, disease duration, disease severity, knowledge of disease, illness perception, comorbidities, depression/anxiety, other psychiatric disorders, cognitive impairment, physical health status (disabilities), (health) literacy level, patient-provider relationship.

In tailoring self-management support there is interplay between patients' needs from a medical perspective and needs from a patient's perspective. Both are important, but to be able to tailor care, providers need to obtain a clear picture of the patient (Ch. 4). In the introduction of this thesis a nurse said she started her consultation by asking: '*Are there any topics you want to discuss today?*' If after probing a patient did not come up with a topic she would leave the self-management part for what it was. Alternatively she could continue exploring the patients' well-being: in general, in the medical domain, in emotions and in role management. This might lead to topics needing further detailing from a medical or from the patient's perspective. This would gradually take the patient to a more active role in health management. By clarifying needs, patient and provider can jointly come to a plan of what needs attention first. This is tailoring on content, based on needs. The next step is to make a customized plan of how the needs will be addressed, and what the role of the patient can be.

In COPD (chronic obstructive pulmonary disease) care various instruments have been developed to assist care providers in gaining insight in patient's needs. The Lung Information Needs Questionnaire (LINQ) measures the patient's need for information about their disease¹³. The Nijmegen Clinical Screening Instrument (NCSI) assists in recognizing and formulating individualized treatment goals and help the caregiver to motivate the patient to adhere to these goals within only a few sessions¹⁴. These can be helpful tools in recognizing patients' needs and to guide content of self-management support accordingly.

After establishing the needs it is important to customize care to the individual patient. Sometimes it can be helpful to actively assess factors that could interfere with self-management support. By jointly setting goals and making an action plan the individual

barriers can be addressed. We found many factors that can impair self-management, but we do not have solutions to conquer all of them. Some factors can be easily addressed, for example by using neighbourhood support in case of patients with a lack of social support or by using social security services in case of patients with financial constraints. Patients can also come up with their own solutions within their range of possibilities. Other factors may require more research to work out effective strategies to support individual patients.

Depression (and other mood disorders), cognitive impairment and (health) literacy are known to be prevalent among chronic disease patients¹⁵⁻¹⁸ and are reported to be associated with impaired self-management¹⁹⁻²², and with negative outcomes of self-management support interventions²³. Therefore, it is important to recognize the presence of these factors and more cautiously approach self-management support in these patients. Future research has to reveal effective ways for dealing with these factors in self-management support. Sometimes it may be best to address these factors first before starting self-management support (e.g. in the case of depression).

Fisher and colleagues also plead for specific attention for cultural differences, such as beliefs and norms²⁴. We also found that illness perceptions are important to explore since these can be so different between patient and care provider. A mismatch in perceptions can influence coping and self-management in patients. Although we could not confirm this, Galdas and colleagues reported gender differences in self-management perception. Physical activity, education and peer-support-based interventions have a positive impact on the quality of life of men²⁵. Zhang and colleagues also found that exploring patients' goals for life may resolve ambivalence and enhance motivation for self-care adherence in patients with heart failure²⁶. Establishing meaningful goals (long term or broad life goals) is a behavioural change technique that helps to motivate the patient to really act in case of a required life style change.

By becoming more aware of the relevant patient factors and by trying to overcome the ones that hamper self-management, more patients will qualify for self-management. However, in some patients self-management is not an option: especially in patients who are too dependent, due to psychiatric disorders, depression, cognitive impairment or addiction, a shift in responsibilities is often not possible.

Recommendations for clinical practice:

- Explore the patients' needs from the patients' perspective and a medical perspective and find out what matters to the patient most to determine where to focus on during the consultation. Another option is using a screening instrument to discover a patient's needs (e.g. NCSI).

- Assess self-management influencing patient factors by means of actual assessment or with a patient-centred approach. In setting goals and making action plans assess patients' motivation, capabilities and opportunities and adapt the plan to the individual. Also, illness perceptions are recommended to explore in patients.
- Specifically assess patients for the presence of depression, health literacy, and cognitive impairment.

Recommendations for future research:

- Future research should continue its efforts of identifying which factors are associated with success from a specific self-management support intervention and what causes that change. A promising design to this purpose is the use of adaptive interventions designs, whereby the type or dosage of the intervention is adapted based on patient characteristics and the treatment is adjusted repeatedly over time²⁷.
- Future research could offer tailored solutions to patients suffering from a depression. Studies could identify whether patients will be better off with a treatment for depression before receiving self-management support, or that a special self-management programme targeted at patients with a depression will be effective. Further research is also required for other effect modifiers, e.g. patients with low literacy, patients with cognitive impairment.
- Future research should identify more effective self-management interventions or programmes for patients and providers to choose from that will support them in self-management. Now care is mostly individualized in content, however in tailoring also differences in way of delivering support is possible (e.g. face-to-face, group sessions, e-health) based on preferences and learning style. This can assist providers in their self-management support.

Reflections on the change in the professionals' role and their needs

Conclusion 4: Nurses need adequate time, tools and training to learn how to apply effective self-management support and to actively change their role during consultations from professional driven to patient centred.

Despite the shift in health care from illness-centred care to patient-centred care, we found that many care providers still have difficulties with adopting the new role that is expected from them. Nurses in our studies also mentioned to be busy with adhering to the clinical guidelines, leaving hardly any time for more patient-centred support. For years the scientific literature emphasizes that professionals should take on the role of coach and need to shift their focus

away from clinical outcomes towards providing help with the day-to-day problems of living with a chronic disease^{28,29}. In our survey among care providers (Ch. 5) we found that two-thirds of care providers consider their role as mainly coaching, whereas one-fifth thinks their role is mainly educative. For the providers who consider their role to be coaching it is questionable whether they know this role is expected from them or they actually fulfil this role. Jansen and colleagues found that Dutch clinicians have not yet adjusted to the new role of patients as active partners in the care process, in which a more coaching attitude is expected from them³⁰. Penn and colleagues also found that the content of consultations focus on assessment of illness progression and medical management, rather than on how people are managing overall and what support they might need³¹. This is not surprising since care providers have often not been taught to take on the role of coach and therefore need to learn and grow into their new role. Nurses in our studies mentioned that additional motivational interviewing courses helped a little in providing more patient-centred care and motivating patients but nurses mentioned that those short courses did hardly influence their practice, as is also known from other literature^{32,33}.

Taylor and colleagues describe that identifying and delivering self-management appropriate to the individual patient at a particular time point is a professional responsibility and a core skill required of the health care professional¹¹. However, we know that this is not a reality yet. Therefore, we aimed to train nurses in delivering adequate self-management support in the Activate intervention (Ch. 7). This means that the care provider assists the patient in gaining insight in his disease and consequences of his disease and helps the patient influence his disease in a positive manner, while the patient remains the expert of his own life. We first studied nurses' needs in supporting patients in their self-management. Important findings that came out were: the need for education in applying behaviour change techniques (BCTs) and effective communication skills. Furthermore, the nurses needed to believe that behaviour change is possible in a patient and that they can assist in achieving behaviour change using BCTs. This requires more knowledge but also a change in attitude towards a new consultation style. They also needed more consultation time, tools to apply BCTs/self-management support and support from other practice care providers. In chapter 4 nurses also mentioned that self-management support needs to be a shared responsibility of the general practice. These findings were comparable to and augmented with findings from an evaluation where the implementation of self-management failed, among others due to nurses considering self-management support no priority³⁴. Another review studying the implementation of self-management support for asthma described that most effective interventions addressed the patient, skill-trained the professionals, and were embedded in an organisation where self-management was valued³⁵.

Recommendations for clinical practice:

- Effective training should be developed and available for care providers to equip them with knowledge on self-management, behaviour change and how to use

behaviour change techniques, and on patient factors that can influence self-management. Furthermore, they need skill training to communicate well with patients and learn how motivation can be increased.

- Care providers need support in adopting their new role as coach to deliver patient-centred care and tailored self-management.
- A change in consultation routine is necessary. Self-management support should be incorporated in routine monitoring strategies, just as well as checking glucose levels in diabetes patients. Providers need enough time with their patients and therefore consultations need to be reorganised in such a matter that self-management is an integrated part of the consultation.

Recommendations for future research:

- More research is necessary to find effective ways of training to support care providers in their change in roles and teach them the necessary skills for self-management support.

Reflections on behaviour change

Conclusion 5: A structured approach encompassing behaviour change techniques will help patients to adequately change their behaviour and thus increase their self-management.

For patients self-management is inevitable and already occurring²⁸. However, it is important to realize that any self-management behaviour that a patient needs to adopt or abandon in order to become a better self-manager requires behaviour change. Behaviour change is difficult to achieve, it requires efforts from a patient but also support from people close to the patient, support from the care provider, and from policy makers. A simple advice is often not enough. In chapter 7 we explored how we could best reach behaviour change in physically inactive patients and found, using the Behaviour Change Wheel, that a structured approach using behaviour change techniques by a care provider could be most effective.

Becoming a self-manager and taking more responsibility in the care process is for many patients a completely new role and highly challenging. If patients are poorly prepared for this new role, this might lead to adverse outcomes. By increasing the role of patients in their disease management, while reducing access to health care services may result in anxiety, coping difficulties, and reduced quality of care³⁶. Therefore, care providers need to support patients in behaviour change. Stenberg & Furness found that, from a patient's perspective, providers of self-management support need to perform multiple roles that address cognitive, behavioural, and emotional aspects of life with a chronic disease³⁷.

Matthias and colleagues studied American veterans and they identified the nurse care manager who administered their educational self-management support as integral to their ability to self-manage. Features they valued most were support with troubleshooting and finding solutions to challenges they were experiencing, goal-setting and progress monitoring, and emotional support and encouragement³⁸.

Besides the care provider supporting patients in self-management a broader and public approach could also be effective in changing people's perceptions and change their behaviours in adapting a healthier lifestyle and becoming more active partners in health.

Recommendations for clinical practice:

- Providers need to be aware that behaviour change is rarely effectuated by a simple advice. Patients need education, learn new skills and applying effective behaviour change techniques can support change.

Recommendations for future research:

- Researchers of future interventions need to consider the importance of behaviour change and think of most effective ways to achieve it. The Medical Research Council (MRC) framework for developing and evaluating complex interventions is very helpful for self-management interventions³⁹. The Behaviour Change Wheel can be used in the development phase of the MRC model to understand the behaviours that need change^{40,41}. The Behaviour Change Wheel provides a systematic way of determining which options are most likely to achieve the change required. Intervention options are linked to the taxonomy of Behaviour Change Techniques (BCTTv1)⁴². This helps clearly identifying 'active' components of the intervention.

Concluding remarks and recommendations

Self-management is currently not well integrated in clinical practice yet. Despite all the scientific efforts to improve the management of chronic diseases, implementation of self-management support remains a challenge to health care systems and professionals. We found that many of the patients with a chronic disease are poorly activated for self-management, suggesting that self-management support is overall still in the planning phase and far from structural implementation in daily practice. Optimal self-management requires a paradigm shift in patients as well as care providers. Patients need to become more active partners in their own health care. The providers are challenged to support the individual patient in their self-management. Throughout this thesis we have identified

many relevant factors that can influence self-management. Tailoring is complex and requires substantial knowledge of the individual patient factors that can influence self-management capacity. By creating more awareness of these factors, more education in behaviour change, and a patient-centred focus it is to be expected that self-management support will become more integrated in routine care and more tailored to the individual.

To wrap up, recommendations for optimal implementation and future research

1. There is a need for clarity and consensus about the concept and the aim of self-management support amongst health care professionals, researchers and policymakers
2. Patient-centred care is conditional for successful and tailored self-management support.
3. Health care professionals need to be adequately equipped and trained to be able to coach and guide the patient in applying self-management.
4. Patients need to be trained and educated in self-management (by the provider but maybe also from a public perspective).
5. Knowledge of factors that determine self-management success and active assessment of these factors will contribute to tailored self-management support.
6. Self-management needs to be valued as a shared responsibility of patients and professionals.
7. Realistic expectations of policymakers and provision of the necessary tools, time and evaluation are necessary for implementation.
8. More effective self-management support programs should become available for patients and providers, with a broad range of interventions (e-health programs, individual programs, group programs) and detailed for specific patient groups (e.g. patients with depression, health literacy, different cultures).

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Summary

Self-management is nowadays seen as an important element in chronic care. Patients only see their care providers a fraction of the time and therefore most of the time they need to take care of themselves. This involves for instance making choices about lifestyle, adhering to medication, taking on new roles that they are able to perform with their chronic illness, handling emotions, monitoring symptoms and knowing when to consult a doctor. This can be quite difficult. Therefore, to self-manage well patients can use some support. Self-management is increasingly embedded in chronic care guidelines; however, implementation in clinical practice is a slow and difficult process. Evidence, from research on self-management interventions, shows that self-management support can have beneficial effects; however, it is not effective in everyone. These interventions are mostly one-size-fits all interventions. The hypothesis underlying this PhD project was that a more tailored approach would lead to more efficacious self-management support. To optimize tailoring of interventions, a thorough understanding of effective intervention ingredients is required, as well as knowledge of tailoring strategies and subgroups of patients in which a given self-management intervention is most effective. Our aim with this thesis was to study patient factors that are of influence on self-management, the perceptions of care providers towards tailoring self-management, how self-management is tailored in clinical practice, what patient factors are involved in tailoring self-management support, and what nurses need to provide tailored self-management support. In **chapter 1** we introduce the concept of self-management and tailoring.

Patient factors

In **chapter 2** we explore what patient factors are associated with activation for self-management. We hypothesized that factors that would be associated with self-management would not depend solely on disease but mostly on patient factors. Via a survey among 1154 patients with diabetes, chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF) and chronic renal disease (CRD) we examined associations between a wide range of socio-demographic, clinical, and psychosocial determinants and patient activation for self-management. We found that age, BMI, educational level, financial distress, physical health status, depression, illness perception, social support and underlying disease were associated with activation for self-management. The regression model including these factors had an explaining variance of 16%. We concluded that, although we found some associations, increased scientific efforts are needed to explain the greater part of the factors that contribute to the complex nature of patient activation for self-management.

In **Chapter 3** we present a literature research that was performed to synthesize the literature on current use of tailoring in heart failure self-management interventions. Furthermore, as building blocks for tailoring, we studied patient characteristics associated with self-management capacity and success of interventions. Within available trials, the

degree to which interventions are explicitly tailored is marginal and often limited to the content (i.e. the focus) of the intervention. We found that certain patient characteristics that are associated with self-management capacity in literature do not influence the effectiveness of a given intervention (i.e. age, gender, ethnicity, disease severity, number of comorbidities) and that other characteristics (low: income, literacy, education, baseline self-management capacity) in fact are indicators for patients with a high likelihood for successful self-management. Increased scientific efforts are needed to continue unraveling success factors of self-management interventions and to validate the modifying impact of currently known patient characteristics.

Care providers' perceptions

In **Chapter 4** we describe a qualitative research in which we interviewed 15 nurses to explore how they perceive self-management, how and when they consider a patient to have potential for self-management, and how they tailor their care accordingly. We used grounded theory as research method and held 15 semi-structured interviews. Four patient typologies emerged from the data: the unmotivated patient, the patient with limited capacities, the oblivious patient and the ideal patient. Nurses elaborated in the interviews on using different approaches for each of these patient subgroups. Nurses' perceptions of self-management substantially impacted how care was individualized. Patient assessment was the key driver of tailoring. Patient assessments were performed in various ways and influenced how and the extent to which care was individualized.

In **Chapter 5** we explore views on self-management support among general practitioners (GPs) and primary care nurses in a survey research. We found that the majority of the 272 care providers involved in the survey see their main role in self-management support as coaching the patient. Most providers aim to stimulate patients to take responsibility for their health behaviour and treatment. Few differences are seen between GPs and nurses; however, nurses more often provide self-management support. Key patient-related factors for successful self-management support, as perceived by both providers, were motivation, knowledge of disease, educational level, self-efficacy, and patient-provider relationship.

To further explore whether these patient factors also influence the *decision making* of care providers regarding the provision of self-management support we performed a clinical vignette study (**chapter 6**). A factorial survey was presented to primary care providers (general practitioners and practice nurses). The survey consisted of clinical vignettes (case descriptions) in which 11 patient factors were systematically varied. Each care provider received a set of 12 vignettes which they evaluated on whether to give a patient self-management support and whether they thought self-management support would be successful for a patient. We found that self-management support is not likely provided in a third of the cases. The most important patient factor in providing self-management

support and expecting that self-management support will be successful was motivation, followed by patient-provider relationship and illness perception. Other factors, such as having a depression or anxiety disorder, education level, self-efficacy and social support, played a minor role in decision-making. Disease, disease severity, knowledge of disease, and age were relatively unimportant factors. Few differences were seen between GPs and nurses. We concluded that the most important factor is motivation and that unmotivated patients are unlikely to receive self-management support. Future tailored interventions should incorporate behaviour change techniques enhancing motivation in unmotivated patients. Furthermore, care providers could be better equipped in stimulating motivational change to enhance self-management in patients.

Behaviour change

Adequate self-management requires behaviour change in both patients and healthcare providers. **Chapter 7** is a protocol paper of the 'Activate' intervention; a nurse-led behaviour change intervention to enhance physical activity of patients at risk for cardiovascular disease. The intervention will be evaluated in a two-armed, cluster randomized controlled trial in primary care. In this chapter we describe the development of this intervention. We used the Behaviour Change Wheel (BCW) as method for designing the intervention. The BCW was applied to analyse what behaviour change is needed of patients to increase their physical activity levels and what behaviour change is needed of nurses to deliver the intervention adequately. We studied nurses' needs in supporting patients to increase their physical activity levels. Based on the outcomes of going through the BCW and nurses' needs we developed a training to equip nurses in supporting patients to enhance their physical activity levels. This study aims to thoroughly evaluate the effectiveness of the Activate intervention and afterwards, to identify patient-related characteristics that modify change in physical activity levels in patients at risk for CVD in primary care.

To conclude, optimal self-management requires a paradigm shift in patients as well as care providers. Throughout this thesis we have identified many relevant factors that can influence self-management. Tailoring is complex and requires substantial knowledge of the individual patient factors that can influence self-management capacity. Care providers need to obtain more knowledge of these factors, and more education in self-management support and behaviour change. When care providers receive more training in these aspects, it is to be expected that self-management support will become more integrated in routine care and more tailored to the individual. In **Chapter 8** we discuss our main findings and give reflections on the concept of self-management and perceptions of professionals, on tailoring of self-management, on the change in the professionals' role and their needs, and on behaviour change. Furthermore, we give implications for clinical practice and future research.





Samenvatting

Zelfmanagement speelt een belangrijke rol in de zorg voor chronisch zieken. Patiënten zien hun zorgverlener(s) maar af en toe en dat betekent dat ze het grootste deel van de tijd voor zichzelf moeten zorgen zonder dat een zorgverlener meekijkt of helpt. Patiënten moeten zelf keuzes maken over hun leefstijl, hun medicijnen goed innemen, nieuwe rollen aannemen die passen in hun leven met een chronische ziekte, omgaan met emoties, symptomen in de gaten houden en weten wanneer ze naar de dokter moeten bij klachten of voor controle. Aangezien dit heel lastig kan zijn, hebben veel patiënten zelfmanagement ondersteuning nodig om te leren betere zelfmanagers te worden. Tegenwoordig wordt zelfmanagement gezien als een belangrijk onderdeel van de zorg voor chronisch zieken en is zelfmanagement ook geïntegreerd in richtlijnen voor chronische aandoeningen. Echter, de implementatie van zelfmanagement in de dagelijkse praktijk blijkt een langzaam en moeizaam proces. Onderzoek laat positieve resultaten zien van zelfmanagement interventies, maar niet bij iedere patiënt. Zelfmanagement interventies worden vaak aan iedere patiënt hetzelfde aangeboden. De verwachting is dat meer patiënten baat kunnen hebben van zelfmanagement ondersteuning als het op maat wordt aangeboden, dus als het aangepast wordt aan het individu. In dit proefschrift hebben we onderzocht welke patiënt factoren van invloed zijn op zelfmanagement vaardigheden. We beschrijven hoe zorgverleners aankijken tegen zelfmanagement ondersteuning en welke ondersteuning zij bieden in de huidige zorg. Ook hebben we onderzocht welke patiënt factoren een rol spelen bij zelfmanagement ondersteuning en wat zorgverleners nodig hebben om zelfmanagement ondersteuning op maat aan te bieden. In **hoofdstuk 1** bespreken we de begrippen zelfmanagement en zorg op maat maken.

Patiënt factoren

In **hoofdstuk 2** onderzoeken we welke patiënt factoren geassocieerd zijn met activatie voor zelfmanagement. Van te voren dachten we dat activatie voor zelfmanagement niet zozeer van de ziekte afhankelijk was, maar vooral van patiënt factoren. Om dit te onderzoeken hebben we een vragenlijst uitgezet onder 1154 patiënten met diabetes, COPD (dit is een Engelstalige afkorting die in het Nederlands chronisch obstructieve long ziekte betekent), chronisch hartfalen en een chronische nierziekte. In deze patiëntengroepen hebben we associaties onderzocht tussen socio-demografische, klinische en psychosociale factoren en activatie voor zelfmanagement. De factoren: leeftijd, BMI, opleidingsniveau, financiële situatie, fysieke gezondheidstoestand, depressie, ziekteperceptie, sociale steun en ziekte waren geassocieerd met activatie voor zelfmanagement. Het regressiemodel waarin deze factoren overbleven had een verklarende variantie van 16%. Op basis hiervan konden we concluderen dat we voor een aantal factoren associaties gevonden hebben, maar dat er nog meer onderzoek nodig is om te verklaren welke factoren nog meer een rol spelen bij activatie voor zelfmanagement.

In **hoofdstuk 3** laten we de resultaten zien van een literatuuronderzoek waarbij we gekeken

hebben naar zorg op maat in zelfmanagement interventies bij hartfalen patiënten. We hebben ook onderzocht welke patiënt factoren geassocieerd zijn met zelfmanagement capaciteit en met baat hebben bij een interventie. In de onderzoeken die we bestudeerd hebben vonden we dat de mate waarin interventies op maat aangeboden worden erg minimaal is en dat wat er op maat gemaakt is vooral de inhoud van de interventie betreft. Er is binnen hartfalen studies best veel onderzoek gedaan naar associaties tussen patiënt factoren en zelfmanagement. Echter, het blijkt dat bepaalde factoren die geassocieerd zijn met zelfmanagement niet per se de effectiviteit van een interventie beïnvloeden (namelijk; leeftijd, geslacht, etniciteit, ziekte ernst, aantal co-morbiditeiten). Andere factoren blijken juist indicatoren voor een hogere kans op succesvol zelfmanagement (namelijk; een laag inkomen, laag niveau van geletterdheid, laag opleidingsniveau en een lage zelfmanagement capaciteit aan de start van een interventie). Er is nog vervolgonderzoek nodig om deze gevonden factoren te valideren en verder te gaan met het ontrafelen van factoren die gepaard gaan met succes van een interventie.

Percepties van zorgverleners

In **hoofdstuk 4** beschrijven we een kwalitatief onderzoek waarin we 15 verpleegkundigen hebben geïnterviewd. In de interviews verkennen we hoe zij naar zelfmanagement kijken, hoe en wanneer zij inschatten dat een patiënt baat zal hebben bij zelfmanagement ondersteuning en hoe ze vervolgens hun zelfmanagement ondersteuning op maat maken. Als onderzoeksmethode hebben we de 'Grounded Theory' (of gefundeerde theorie) toegepast en 15 semi gestructureerde interviews gehouden. Uit de data konden we 4 patiënt typologieën onderscheiden: de ongemotiveerde patiënt, de patiënt die het niet kan, de afhankelijke patiënt en de ideale patiënt. In de interviews vertelden de verpleegkundigen dat ze verschillende benaderingen toepasten voor deze subgroepen van patiënten. De ideeën van verpleegkundigen over zelfmanagement beïnvloedde hoe zelfmanagement werd vormgegeven en hoe het op maat gemaakt wordt. Het maken van een inschatting van een patiënt, over hoe goed de patiënt in staat zal zijn in zelfmanagement, werd op verschillende manieren vormgegeven; het liep uiteen van het uitgebreid uitvragen van specifieke factoren tot het maken van een impliciete inschatting op basis van een indruk en voorkennis van de patiënt. Deze inschatting van de patiënt beïnvloedde het meest hoe zelfmanagement op maat gemaakt werd.

In **hoofdstuk 5** verkennen we met een vragenlijst ideeën over zelfmanagement van een grotere groep zorgverleners, huisartsen en praktijkondersteuners/verpleegkundigen. We zagen dat de meerderheid van de 272 zorgverleners hun rol in zelfmanagement ondersteuning als voornamelijk coachend ziet. Hun voornaamste doel met het toepassen van zelfmanagement ondersteuning is de patiënt een actieve rol en verantwoordelijkheid laten nemen over zijn behandeling, gedrag en gezondheid. We zagen weinig verschillen tussen huisartsen en praktijkondersteuners in hun ideeën over zelfmanagement, wel zien

we dat praktijkondersteuners vaker zelfmanagement ondersteuning bieden aan patiënten dan huisartsen. De zorgverleners vonden motivatie, kennis van de ziekte, opleidingsniveau, vertrouwen in eigen kunnen en de behandelrelatie de belangrijkste factoren voor succesvolle zelfmanagement ondersteuning.

Vervolgens wilden we verkennen in welke mate patiënt factoren een rol spelen bij de besliskunde van zorgverleners in het aanbieden van zelfmanagement. Dit hebben we gedaan met een klinische vignetten studie (**hoofdstuk 6**). We hebben een vragenlijst voorgelegd aan huisartsen en praktijkondersteuners, die bestond uit 12 klinische vignetten. De vignetten zijn korte patiënt beschrijvingen waarin 11 patiënt factoren systematisch gevarieerd zijn. Zorgverleners moesten elke casus beoordelen of ze zelfmanagement aan zouden bieden aan de patiënt en of ze dachten dat zelfmanagement ondersteuning succesvol zou zijn. We vonden dat zelfmanagement ondersteuning in 30% van de casus niet waarschijnlijk werd aangeboden. De belangrijkste factor bij het wel of niet aanbieden van zelfmanagement ondersteuning was motivatie, gevolgd door behandelrelatie en ziekte perceptie. Andere factoren zoals het hebben van een angst- of stemmingsstoornis, opleidingsniveau, vertrouwen in eigen kunnen en sociale steun speelden een kleine rol in de besliskunde. Ziekte, ziekte-ernst, kennis van de ziekte en leeftijd waren relatief onbelangrijke factoren. Huisartsen beschouwden ziekte-perceptie van meer belang dan POHs. We concludeerden dat motivatie veruit de belangrijkste factor is. Patiënten die ongemotiveerd zijn voor zelfmanagement zullen waarschijnlijk geen zelfmanagement aangeboden krijgen. Om zelfmanagement interventies effectiever te maken zal meer aandacht moeten gaan naar het vergroten van motivatie bij ongemotiveerde patiënten. Ook zullen zorgverleners beter toegerust moeten worden om motivatie te stimuleren bij patiënten, zodat meer patiënten zelfmanagement ondersteuning zullen krijgen.

Gedagsverandering

Adequaat zelfmanagement vraagt om gedragsverandering in zowel patiënten als zorgverleners. In **hoofdstuk 7** beschrijven we in een onderzoeksprotocol de ontwikkeling van een interventie en hoe de “In Actie” studie eruit gaat zien. De In Actie studie is een gedragsverandering interventie voor patiënten met een verhoogd risico op hart- en vaatziekten (o.a. patiënten met een verhoogde bloeddruk, verhoogd cholesterol en/of diabetes). De studie wordt uitgevoerd door de praktijkondersteuner van de huisarts om patiënten te ondersteunen bij meer gaan bewegen. De interventie wordt geëvalueerd in een tweearmig cluster gerandomiseerd onderzoek in de eerste lijn. In dit hoofdstuk beschrijven we uitgebreid de ontwikkeling van deze interventie met behulp van het Behaviour Change Wheel (afgekort BCW, dit is een methode vanuit Engeland om een gedragsverandering interventie te ontwikkelen). We hebben het BCW gebruikt om te analyseren welke gedragsverandering(en) er nodig zijn bij patiënten om meer te gaan bewegen en welke gedragsverandering(en) er nodig zijn bij praktijkondersteuners om de

interventie uit te voeren zoals is bedoeld. We hebben onderzocht wat praktijkondersteuners nodig hebben om patiënten te ondersteunen bij het meer gaan bewegen. Op basis hiervan en van de uitkomsten van het doorlopen van het BCW hebben we een training ontwikkeld om praktijkondersteuners toe te rusten voor het ondersteunen van patiënten bij het meer gaan bewegen. Deze studie heeft als doel te onderzoeken of deze interventie effectief is en goed te evalueren waarom deze interventie wel of niet effectief is en vervolgens te onderzoeken welke patiënt factoren geassocieerd zijn met een toename in bewegen.

Tot slot kunnen we concluderen dat optimaal zelfmanagement vraagt om een fundamentele verandering in de denkwijze en het handelen van patiënten en hun zorgverleners. Van de patiënt wordt een meer actieve rol gevraagd en van de zorgverlener een coachende rol. Door het proefschrift heen hebben we veel relevante patiënt factoren kunnen identificeren die van invloed kunnen zijn op zelfmanagement. Zelfmanagement op maat maken is complex en vraagt om aanzienlijke kennis van de individuele patiënt factoren die het zelfmanagement van een patiënt kunnen beïnvloeden. Daarnaast is meer inzicht, in wat zelfmanagement ondersteuning is en hoe zij dat kunnen aanbieden, belangrijk om gedragsverandering bij de patiënt te bewerkstelligen. We verwachten dat zelfmanagement ondersteuning meer geïntegreerd kan worden in de dagelijkse zorg als zorgverleners hier meer in worden geschoold en dat zelfmanagement ondersteuning dan meer op het individu kan worden aangepast. In **hoofdstuk 8** discussiëren we over onze belangrijkste bevindingen en reflecteren we op het begrip zelfmanagement en percepties van zorgverleners hierover, het op maat maken van zelfmanagement ondersteuning, de verandering in de rol van de zorgverlener en wat de zorgverlener nodig heeft om te veranderen, en op gedragsverandering. Ook geven we in dit hoofdstuk implicaties voor de praktijk en voor toekomstig onderzoek.



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*The Lord is gracious and compassionate,
Slow to anger and rich in love.
Praise the Lord, oh my soul, praise the Lord.*





Curriculum Vitae

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Irene Bos-Touwen was born on October 22nd 1983 in Driebergen-Rijsenburg, the Netherlands. She graduated from secondary school in 2001 at the Breul in Zeist. In that same year she started with pharmaceutical sciences at the Utrecht University. She completed her first year and afterwards started her medical training at the Utrecht University. She did several optional subjects, of which an internship gynaecology and obstetrics in Paramaribo, Surinam. After graduation in 2009 she worked as a resident at the emergency department of the Sint Antonius Hospital in Utrecht. In 2010 she worked as a resident at the department of Paediatrics in the Wilhelmina's Children hospital in Utrecht. This was followed by a residency in a nursing home of Riethorst Stromenland in Almkerk. In 2011 she started her general practitioner vocational training at the University Medical Center Utrecht. In 2012, she combined this with her research described in this thesis under supervision of Prof. Dr. M.J. Schuurmans, Prof. Dr. N.J. de Wit and Dr. J.C.A. Trappenburg. She obtained her Master of Science degree in Clinical Epidemiology at the Utrecht University in 2016. In September 2016 she will start with her final year of the general practitioner vocational training.