

# Associations between patient characteristics and self-management capacity in patients with type 2 diabetes

---

*A cross-sectional study*

<b>Student</b>	C.M.A. (Lotte) Spruit-Bentvelzen
<b>Student number</b>	3696782
<b>Course</b>	Master thesis
<b>Version</b>	Final version
<b>Date</b>	July 3 <sup>rd</sup> 2013
<b>Supervisor</b>	Dr. J.C.A. Trappenburg
<b>Course instructor</b>	Dr. H. van Os-Medendorp
<b>Location internship</b>	Department of Rehabilitation, Nursing Science & Sports, University Medical Center Utrecht
<b>Journal</b>	Diabetes Care
<b>Reference style</b>	Uniform Requirements for Manuscript submitted to Biomedical Journals
<b>Words (requirement journal)</b>	4000
<b>Words (text)</b>	3.407
<b>Words (English abstract)</b>	300
<b>Words (Dutch abstract)</b>	300

*Master Clinical Health Science, Nursing Science, Utrecht University*

## 1. Introduction

Diabetes mellitus is a worldwide public health problem, with 347 million patients in 2012 (1). Diabetes is projected to become the seventh cause of death in the world by the year 2030 (1). Type 2 diabetes (DM-II) accounts for around 90% of all diabetes and results from the body's ineffective use of insulin (1). Since DM-II cannot be cured, increasing importance is given to focus the treatment on enhancing glycemic control, which has shown to reduce diabetes-related complications, such as cardiovascular disorders, blindness, renal failure, and amputations (2, 3).

Since DM-II is a chronic illness, patients need to self-manage their disease on a day-to-day basis (4). Self-management is the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition (5). Effective self-management requires a high level of control on the part of the patient, deliberate decision making and problem solving, and some autonomy with respect to adjusting the necessary regimen (6). Patients with the skills, knowledge, and motivation to participate as effective self-managers are referred to as 'activated patients'. Higher patient activation levels are associated with better diabetes self-management (7). Therefore, in previous research, measures of patient activation were used to determine levels of self-management capacity (8).

In the Netherlands, most diabetes care is provided in general practices (9), involving both General Practitioners (GPs) and practice nurses for diabetes (10). In 2008, 72% of all Dutch diabetics received care from a practice nurse, a substantial growth compared to preceding years (11). For nurses in a primary care setting, activating patients in becoming effective and informed self-managers is an essential element of high quality chronic illness care (12). Self-management support can result in physical and psychological patient benefits, and in some cases reduce their dependence on service use (13). However, it is likely that certain patients only need some self-management assistance in controlling their disease, while others only benefit from more intense self-management support (14).

Although customizing support to an individual's characteristics and situation could increase the likelihood of sustained self-management (15), in daily practice this is too time-consuming. Therefore, identifying which subgroups of patients, based on patient and disease characteristics, need special attention regarding self-management could be of great value for nurses in targeting support. In previous research younger, higher educated, and healthier participants were found to be better self-managers (16). Diabetes self-management capacity was also positively associated with social support (6, 17, 18), illness perception (19), and quality of life (20) and negatively associated with anxiety (21) and depression (4, 22). However, these findings were never combined in one study to identify key variables.

## **2. Problem statement, Aim and Research Questions**

### **Problem statement**

Earlier research focused on a limited set of patient and disease specific characteristics related to self-management capacity, each paper identifying one or a few characteristics at most. However, in order to identify which subgroups of patients need more intense self-management support, multiple characteristics that have shown associations with self-management capacity, should be combined to expose key determinants. Secondly, determining the distribution of self-management capacity levels in patients with DM-II is needed to gain insight into the size of these subgroups of poor self-managers.

### **Aim**

The aim of this study was to identify which key patient and disease characteristics are associated with (poor) self-management capacity in patients with DM-II and to determine the distribution of self-management capacity levels, to enhance targeting self-management support.

### **Research questions**

1. Which patient and disease characteristics are associated with self-management capacity in adult patients with DM-II?
2. What is the distribution of self-management capacity levels in patients with DM-II?
3. Which patient and disease characteristics increase the risk of being a poor self-manager?

## **3. Method**

### **Study design**

A quantitative, observational, explorative, cross-sectional study was carried out, as this is the best design to describe relationships between diabetes self-management and patient characteristics at a fixed point in time (23). Data were collected through questionnaires and chart review.

### **Setting**

Patients with DM-II were recruited from two primary health clinics with a total of six GPs. Patients were selected by their own GP through their electronic database in January and February 2013. All selected patients received an envelope including an invitational letter to participate in the study, on behalf of their GP, study information, an informed consent form, the questionnaire, and a pre-addressed return envelope from the researcher. Patients were asked to return the signed informed consent form and the completed questionnaire. By signing the informed consent form, patients gave

permission for chart review, of which the extent was explained in the study information. Three weeks after the first mailing, a reminder questionnaire was mailed in case of non-response (23).

## **Participants**

The study included adult patients with a clinical diagnosis of DM-II (fasting plasma glucose  $\geq 7.0$  mmol/l or 2h plasma glucose  $\geq 11.1$  mmol/l). Exclusion criteria included severe cognitive impairment (e.g. a reported Mini-Mental State Examination below 22 points (24)), non-Dutch speaking, and terminal illness from any cause (life expectancy of less than three months), at the GP's discretion.

## **Study variables**

### Dependent variable

The dependent variable of the study was the level of self-management capacity, which was measured as 'patient activation' with the Patient Activation Measure (PAM-13). The PAM is a 13-item, interval-level, one-dimensional scale, assessing patient self-reported knowledge, skills and confidence for self-management of one's chronic condition (12, 25). It classifies respondents into four activation levels (26). The total score ranges from 0 – 100, with level one being the lowest (score  $\leq 47.0$ ), and level four being the highest (score  $\geq 67.1$ ), dividing level two and three at 55.1 (8, 26). In this study, level one is considered poor activation. A higher score on the PAM is positively associated with self-management (16). The PAM-13 is translated into Dutch and found to be reliable to measure patient activation. The level of internal consistency is good ( $\alpha=0.88$ ), inter-item correlations are moderate to strong ( $r=0.46 - 0.66$ ). The test-retest reliability was moderate ( $r=0.47$ ) (16). The measure maintains precision across different demographic and health care groups, including chronically ill patients (12, 16).

### Independent variables

#### *Demographic variables*

This study includes the following demographic variables: gender, age, Body Mass Index (BMI), living situation, education, working status, self-reported financial situation, ethnicity, and smoking status, collected through self-report.

#### *Self reported health status*

Self-reported health status was measured using the Short Form-12 (SF-12), the shorter alternative to the SF-36, which measures physical and mental health status by means of two summary scores: a physical component summary (PCS) and mental component summary (MCS) (27). It contains 12 items from the SF-36, including one or two items from each of the eight SF-36 subscales (28). A

zero score indicates the lowest level of health and 100 the highest. Use of the SF-12 as a shorter version of the SF-36 in Dutch studies is supported (27).

### *Depression and anxiety*

To measure the possible presence of anxiety and depressive states, the Hospital Anxiety and Depression Scale (HADS) was used (29). The 14-item self-report screening scale is divided into two 7-item subscales: one for anxiety and one for depression (29). Each item scores from 0 – 3, with a total score of 0 – 21 per subscale. A score >10 indicates anxiety or depression (30). In a validation study in different groups of Dutch subjects, the HADS showed a stable dimensional structure and reliability across medical settings and age groups, including general practice patients (31).

### *Illness Perception*

The Brief Illness Perception Questionnaire (B-IPQ), a 9-item scale, was used to measure illness perception (32). Five items assess cognitive illness representations: consequences, timeline, personal control, treatment control, and identity. Two items assess emotional representations: concern and emotions. One item assesses illness comprehensibility and one open-ended response item assesses causal representation. All of the items, except the causal question, are rated on an 0 – 10 scale (32). A lower score indicates a more positive illness perception. The Dutch version of the B-IPQ (Brief IPQ-DLV) showed face and content validity, and moderate to good reliability (33).

### *Social Support*

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS), a 12-item scale measuring perceived social support from Family, Friends, and a Significant Other (34). Each item is scored on a scale from 1 – 7, with a possible total range of 12 – 84. The higher the sum of the 12 items, the higher the level of social support. The validity and reliability of the Dutch version were confirmed (35).

### *Disease specific data from the patient's file*

Disease specific data, collected by chart review, included duration of the disease (in years), most recent HbA<sub>1c</sub>, type of medication, diabetic complications (diabetic retinopathy, neuropathy, nephropathy, and diabetic ulcers), and co-morbidity (number of chronic illnesses).

### **Sample size**

It is indicated that 20:1 is a desirable ratio of participants to parameters in linear regression analysis, but 10:1 is more realistic (36). With the 20 parameters of this study, a sample size of 200 was needed. However, for logistic regression analysis a 20:1 ratio was required (37). Therefore, with an expected response-rate of 40% (23) and almost 800 diabetics, all eligible patients of the general practices were to receive the questionnaire.

### **Statistical analysis**

All data were analysed using Statistical Package for the Social Sciences (SPSS), version 21.0. Missing values within questionnaires were dealt with according to the guidelines. Since the final dataset contained <2% missing values, missing cases were excluded listwise in analysis (38). Frequencies, percents, range, means and standard deviations (SD) were used to describe baseline characteristics and to establish the distribution of levels of self-management capacity. A scatterplot and correlation-matrix were made of all continuous variables to confirm linearity and detect outliers and multicollinearity. Histograms for the residuals and normal probability plots were produced to review the distributions of the variables. Dummy-variables were created to deal with categorical variables.

Due to the presence of categorical variables, associations were established using linear regression analysis between activation and each variable ( $p \leq 0.05$ ) (23). The  $\beta$  and p-values were reported. Multiple linear regression analyses were conducted with all significant variables ( $p \leq 0.05$ ) to model the relationship between characteristics and activation, using the Enter-method, eliminating variables one by one if  $p \geq 0.1$ , to increase transparency of the elimination process. Dummy-variables were added in blocks. The model summary was reported including  $\beta$  and p-values. Then, logistic regression analyses were conducted in a similar way, but with level one (poor) activation as dependent variable and all other variables as independent variables to establish which characteristics increased the likelihood of being a poor self-manager.

### **Ethical considerations**

All data were dealt with anonymously. The study was approved by the Medical Research Ethics Committee of the University Medical Center Utrecht.

## **4. Results**

A total of 772 patients met the inclusion criteria and received the questionnaire. Of these, 454 patients (58.8%) returned a filled in questionnaire of which ten did not include a signed informed consent form, even after a reminder was sent. Therefore, 444 (57.5%) patients were eligible for analysis (Figure 1). No characteristics were known from non-responders.

### **Sample characteristics**

Table 1 shows the baseline characteristics of the included patients. Participants had a mean age of 68 years ( $\pm 10.8$ , range 28 – 92 years), 56% was male. Mean duration of their disease was 6.7 years ( $\pm 4.4$ ). In general, participants suffered from mild diabetes, since most patients used no (46%) or oral (38%) medication and had no diabetes related complications (88%). Half of the participants suffered from at least one co-morbidity. The majority of the patients were retired (60%), living with

their partner (63%) and of Dutch origin (96%). There were more low (50%) and medium (36%) educated patients than high (14%). About half of the respondents reported a comfortable financial situation (52%), only 9% could not manage financially. A majority had a history of smoking (69%), but most of them had quit.

Table 2 shows the results of the questionnaires. Activation scores were normally distributed and classified 22.9% of the participants in level one, 25.3% in level two, 38.5% in level three and 13.2% in level four (Figure 2), with a mean activation score of 55.2 ( $\pm 11.1$ ). Most patients did not suffer from depression (93.1%  $< 10$ ) or anxiety (92.3%  $< 10$ ). Only a minority (16.9%) experienced poor social support. Illness perception was moderate and self-reported health was moderate to good. A correlation matrix of all continuous variables showed no multicollinearity (data not shown).

### **Linear regression analysis**

In bivariate analysis (Table 3), activation was associated with depression ( $\beta = -0.90$ ,  $p < 0.001$ ), anxiety ( $\beta = -0.77$ ,  $p < 0.001$ ), self-reported health status ( $\beta = 0.12$ ,  $p < 0.001$ ), social support ( $\beta = 0.20$ ,  $p < 0.001$ ), illness perception ( $\beta = -0.25$ ,  $p < 0.001$ ) and ethnicity ( $\beta = -6.70$ ,  $p = 0.018$ ). Furthermore, patients with a medium ( $\beta = -4.57$ ,  $p < 0.001$ ) or insufficient ( $\beta = -6.13$ ,  $p = 0.001$ ) self-reported financial situation had significant lower activation scores than patients with a comfortable financial situation. A positive association was found between activation and high education versus low ( $\beta = -4.26$ ,  $p = 0.010$ ) and medium ( $\beta = -4.04$ ,  $p = 0.019$ ). Activation decreased as the number of co-morbidities increased, being statistically significant for having two or more chronic illnesses compared to absence of co-morbidities ( $\beta = -3.82$ ,  $p = 0.015$ ). Inability to work was associated with lower activation compared to any other work status, except being unemployed ( $p = 0.085$ ). Finally, BMI almost reached significance ( $\beta = -0.25$ ,  $p = 0.051$ ). All other results are shown in table 3.

Based on the bivariate analysis, all factors significantly affecting activation ( $p \leq 0.05$ ) were entered into a multiple linear regression analysis. Based on  $p$ -values  $> 0.1$ , variables were eliminated in the following order: work status, financial situation, self-reported health, anxiety, ethnicity, education level and presence of co-morbidities. A total of three variables remained: depression, social support and illness perception (Table 4), explaining 14.1% of the variance in activation levels.

### **Logistic regression analysis**

Logistic regression analysis identified ten variables that were significantly associated with poor activation ( $p \leq 0.05$ ) (Table 5). The sample size allowed multivariate analysis, in which seven variables were eliminated based on  $p$ -values  $> 0.1$  in the following order: financial situation, anxiety, ethnicity, BMI, living situation, depression and education. In the final logistic model, risk of poor activation was associated with low self-reported health ( $p = 0.003$ ,  $OR = 0.984$ ,  $CI = 0.973 - 0.994$ ), negative illness perception ( $p = 0.004$ ,  $OR = 1.035$ ,  $CI = 1.011 - 1.060$ ) and poor social support

( $p=0.022$ ,  $OR=0.981$ ,  $CI=0.966 - 0.997$ ) (Table 6). The overall rate of correct classification through the model was 77.6%, only 1% better than prediction without the model.

## 5. Discussion

The study reveals that in this sample of diabetics almost half of the patients had activation level one or two, indicating they do not yet understand why or how to be activated patients. The group with level three was the largest. These patients are becoming activated patients but still need to develop skills and confidence to support their new behaviours (8). Only a minority had the highest level. Furthermore, the study showed significant associations between activation and depression, social support and illness perception in multivariate linear analysis. However, the combination of variables could explain only 14.1% of the variance in activation. Also, low self-reported health, negative illness perception, and poor social support increased likelihood of poor activation, but with odds ratios of approximately one, these variables barely increased correct classification of poor self-managers.

Although many results of this study were also found in earlier research (6, 16-18, 20), identifying key characteristics was never possible, since previous studies focused on a limited set of determinants and results could not be combined due to different samples. After exploring twenty patient and disease characteristics in this study, (poor) social support and (negative) illness perception appear to be of main importance. Both are not just associated with activation, but are also significant determinants in identifying poorly activated patients. While this knowledge only provides a very small advantage in finding poorly activated patients, these determinants deserve attention in diabetic care, especially since both illness perception and social support are also major determinants in the process of improving activation (22). In addition, special interest should also be given to signs of depression, since depression is not only related to poor activation, but also to worse diabetes regulation and more hospital admissions (22). Periodic consultations by practice nurses, which are common in Dutch diabetic care, are a good opportunity to gain information regarding above-mentioned characteristics, including self-reported health. In interpreting the results, it is important that cross-sectional data cannot determine directionality or causality, and additional research is needed to further examine the findings of the study.

Some results of the study differ from earlier research. First, in comparison to previous studies on activation in chronically ill patients, the number of patients in this study with level one seemed fairly moderate, but more patients with level four were to be expected. In line with that, mean PAM scores in this study were lower than in other studies (scores 61.3 – 69.3) (7, 16, 39). Two studies had more comparable mean scores (53.2 – 56.6) (40, 41). The study samples were very diverse regarding gender, disease, health and ethnicity, but mean age differences of the samples were prominent,

with higher mean scores in younger samples (<60). Although our study found no associations between activation and age, earlier research did (16) and it could explain the lower mean activation in our relatively old sample. Furthermore, this study is the first to reveal associations between activation and disability. However, the group of disabled participants was very small, which threatens the validation of the findings.

A strength of this study is the high response-rate, resulting in a 20:1 ratio of participants to parameters, which is substantially higher than the expected 10:1 ratio and allowed multiple logistic regression analysis. This study also has some limitations that should be discussed. First, patients were asked about their activation regarding diabetes. However, in case of multi-morbidity, activation could be influenced by another chronic illness, making it hard, if not impossible, to answer the questions purely for diabetes. Another chronic illness might also be of much bigger influence on their activation than diabetes, in which case their results might reflect activation regarding their other illness. Secondly, retrieving data from the patient's medical file could be susceptible to wrong interpretation. However, the researcher is a nurse and therefore familiar with medical terminology. Also, 5% of the chart review was double-checked by one of the GPs, which reduced interpretation bias. Finally, only 3.6% of the participants was of foreign origin. While this percentage is comparable in the overall population of the general practices, the prevalence of diabetes is higher in foreigners than in natives in the Netherlands and a higher percentage was to be expected in the sample (42). The small number could partially be explained by the exclusion of non-Dutch speaking patients, but might also be due to attrition bias. Therefore, associations between activation and ethnicity should be interpreted with a certain restraint.

This study is only a first step in targeting self-management support. Unfortunately, simple patient and disease characteristics, usually already known or easy to get hold of, only explain a small part of variance in activation. As suggested in earlier research, personality traits or other psychological or environmental factors might explain a larger part of the variance (22). Levels of activation might also be influenced by caregiver behaviour or management strategies. A recent study that included both socio-demographical and psychological determinants, such as personality and provider-patient communication, could already explain 25% of the variance in activation scores (18). Therefore, future research regarding patient activation should focus more on behavioural aspects. Qualitative research might be useful to explore in depth why some patients are good and some are poor self-managers.

## 6. Conclusion

Overall, this study shows that many diabetic patients still need support in managing their own health, since almost half of the patients had activation level one or two and only a minority had the highest level. Furthermore, results show that diabetes activation is associated with several patient and disease characteristics, mainly social support, depression and illness perception. Social support and illness perception combined with self-reported health status, are also important in identifying poorly activated patients and deserve more attention in self-management support by practice nurses. Nevertheless, even with exploration of twenty variables, variance in activation remains unexplained for the greater part and it is challenging as ever to identify patients in need of more self-management support.

## 7. Recommendations

- Attention for poor social support, low illness perception, depression and low self-reported health should be incorporated in everyday primary health care for diabetic patients.
- Longitudinal research is recommended to overcome the limitations raised by this study's cross-sectional design.
- Due to limitations of the sample, further research is needed regarding associations with disability and ethnicity.
- Further research should be conducted, focusing on psychological properties such as caregiver and patient behaviour.

## 8. Reference list

1. Diabetes fact sheet [Internet].: World Health Organization (WHO); 2013 [updated 2013 Mar; cited 2013 Jun 10]. Available from: <http://www.who.int/mediacentre/factsheets/fs312/en/index.html>.
2. Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). UK prospective diabetes study (UKPDS) group. *Lancet*. 1998 Sep 12;352(9131):837-53.
3. Inzucchi SE, Bergenstal RM, Buse JB, Diamant M, Ferrannini E, Nauck M, et al. Management of hyperglycemia in type 2 diabetes: A patient-centered approach: Position statement of the american diabetes association (ADA) and the european association for the study of diabetes (EASD). *Diabetes Care*. 2012 Jun;35(6):1364-79.
4. Cramm JM, Nieboer AP. Self-management abilities, physical health and depressive symptoms among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Patient Educ Couns*. 2012 Jun;87(3):411-5.
5. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. *Patient Educ Couns*. 2002 Oct -Nov;48(2):177-87.
6. Gallant MP. The influence of social support on chronic illness self-management: A review and directions for research. *Health Educ Behav*. 2003 Apr;30(2):170-95.
7. Rask KJ, Ziemer DC, Kohler SA, Hawley JN, Arinde FJ, Barnes CS. Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. *Diabetes Educ*. 2009 Jul-Aug;35(4):622-30.
8. Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? *Health Serv Res*. 2007 Aug;42(4):1443-63.
9. Diabetes mellitus: Hoe zijn preventie en zorg georganiseerd? [Internet]. Bilthoven: Rijksinstituut voor Volksgezondheid en Milieu (RIVM); 2013 [updated 2013 Jun 13; cited 2013 Jun 19]. Available from: <http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/endocriene-voedings-en-stofwisselingsziekten-en-immuniteitsstoornissen/diabetes-mellitus/diabetes-mellitus-preventie-en-zorg/>.
10. Gorter KJ, Tuytel GH, de Leeuw JR, van der Bijl JJ, Bensing JM, Rutten GE. Preferences and opinions of patients with type 2 diabetes on education and self-care: A cross-sectional survey. *Diabet Med*. 2010 Jan;27(1):85-91.
11. Heijmans M, Spreeuwenberg P, Rijken M. Ontwikkelingen in de zorg voor chronisch zieken. rapportage 2010. Utrecht: Nederlands instituut voor onderzoek van de gezondheidszorg (NIVEL); 2010 Aug 2010.
12. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004 Aug;39(4 Pt 1):1005-26.
13. Coster S, Norman I. Cochrane reviews of educational and self-management interventions to guide nursing practice: A review. *Int J Nurs Stud*. 2009 Apr;46(4):508-28.

14. Trappenburg J, Jonkman N, Jaarsma T, van Os-Medendorp H, Kort H, de Wit N, et al. Self-management: One size does not fit all. *Patient Educ Couns*. 2013 Mar 14.
15. Radhakrishnan K. The efficacy of tailored interventions for self-management outcomes of type 2 diabetes, hypertension or heart disease: A systematic review. *J Adv Nurs*. 2012 Mar;68(3):496-510.
16. Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in the netherlands: Translation and validation of the american short form patient activation measure (PAM13). *BMC Public Health*. 2012 Jul 31;12(1):577.
17. Hunt CW, Grant JS, Pritchard DA. An empirical study of self-efficacy and social support in diabetes self-management: Implications for home healthcare nurses. *Home Healthc Nurse*. 2012 Apr;30(4):255-62.
18. Tahmasebi R, Noroozi A, Tavafian SS. Determinants of self-management among diabetic patients: A path analysis. *Asia Pac J Public Health*. 2013 Feb 17.
19. Leventhal H, Weinman J, Leventhal EA, Phillips LA. Health psychology: The search for pathways between behavior and health. *Annu Rev Psychol*. 2008;59:477-505.
20. Cochran J, Conn VS. Meta-analysis of quality of life outcomes following diabetes self-management training. *Diabetes Educ*. 2008 Sep-Oct;34(5):815-23.
21. Janzen Claude JA, Hadjistavropoulos HD, Friesen L. Exploration of health anxiety among individuals with diabetes: Prevalence and implications. *J Health Psychol*. 2013 Jan 24.
22. Snoek FJ, Hogenelst MH. Psychological implications of diabetes mellitus. *Ned Tijdschr Geneeskd*. 2008 Nov 1;152(44):2395-9.
23. Polit DF, Beck CT. *Nursing research. generating and assessing evidence for nursing practice*. Eighth ed. Philadelphia: Lippincott Williams & Wilkins; 2008.
24. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975 Nov;12(3):189-98.
25. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005 Dec;40(6 Pt 1):1918-30.
26. Chubak J, Anderson ML, Saunders KW, Hubbard RA, Tuzzio L, Liss DT, et al. Predictors of 1-year change in patient activation in older adults with diabetes mellitus and heart disease. *J Am Geriatr Soc*. 2012 Jul;60(7):1316-21.
27. Mols F, Pelle AJ, Kupper N. Normative data of the SF-12 health survey with validation using postmyocardial infarction patients in the dutch population. *Qual Life Res*. 2009 May;18(4):403-14.
28. Gandek B, Ware JE, Aaronson NK, Apolone G, Bjorner JB, Brazier JE, et al. Cross-validation of item selection and scoring for the SF-12 health survey in nine countries: Results from the IQOLA project. international quality of life assessment. *J Clin Epidemiol*. 1998 Nov;51(11):1171-8.
29. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983 Jun;67(6):361-70.

30. Crawford JR, Henry JD, Crombie C, Taylor EP. Normative data for the HADS from a large non-clinical sample. *Br J Clin Psychol*. 2001 Nov;40(Pt 4):429-34.
31. Spinhoven P, Ormel J, Sloekers PP, Kempen GI, Speckens AE, Van Hemert AM. A validation study of the hospital anxiety and depression scale (HADS) in different groups of dutch subjects. *Psychol Med*. 1997 Mar;27(2):363-70.
32. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. *J Psychosom Res*. 2006 Jun;60(6):631-7.
33. de Raaij EJ, Schroder C, Maissan FJ, Pool JJ, Wittink H. Cross-cultural adaptation and measurement properties of the brief illness perception questionnaire-dutch language version. *Man Ther*. 2012 Aug;17(4):330-5.
34. Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the multidimensional scale of perceived social support. *J Pers Assess*. 1990 Winter;55(3-4):610-7.
35. Pedersen SS, Spinder H, Erdman RAM, Denollet J. Poor perceived social support in implantable cardioverter defibrillator (ICD) patients and their partners: Cross-validation of the multidimensional scale of perceived social support. *Psychosomatics: Journal of Consultation Liaison Psychiatry*. 2009 Sep-Oct;50(5):461-7.
36. Xu Y, Toobert D, Savage C, Pan W, Whitmer K. Factors influencing diabetes self-management in chinese people with type 2 diabetes. *Res Nurs Health*. 2008 Dec;31(6):613-25.
37. Park HA. An introduction to logistic regression: From basic concepts to interpretation with particular attention to nursing domain. *J Korean Acad Nurs*. 2013 Apr;43(2):154-64.
38. Graham JW. Missing data analysis: Making it work in the real world. *Annu Rev Psychol*. 2009;60:549-76.
39. Fowles JB, Terry P, Xi M, Hibbard J, Bloom CT, Harvey L. Measuring self-management of patients' and employees' health: Further validation of the patient activation measure (PAM) based on its relation to employee characteristics. *Patient Educ Couns*. 2009 Oct;77(1):116-22.
40. Skolasky RL, Green AF, Scharfstein D, Boulton C, Reider L, Wegener ST. Psychometric properties of the patient activation measure among multimorbid older adults. *Health Serv Res*. 2011 Apr;46(2):457-78.
41. Ryvicker M, Peng TR, Feldman PH. Patient activation and disparate health care outcomes in a racially diverse sample of chronically ill older adults. *J Health Care Poor Underserved*. 2012;23(4):1577-89.
42. Ujic-Voortman JK, Schram MT, Jacobs-van der Bruggen MA, Verhoeff AP, Baan CA. Diabetes prevalence and risk factors among ethnic minorities. *Eur J Public Health*. 2009 Oct;19(5):511-5.

## 9. Figures and tables

Figure 1 | Flowchart

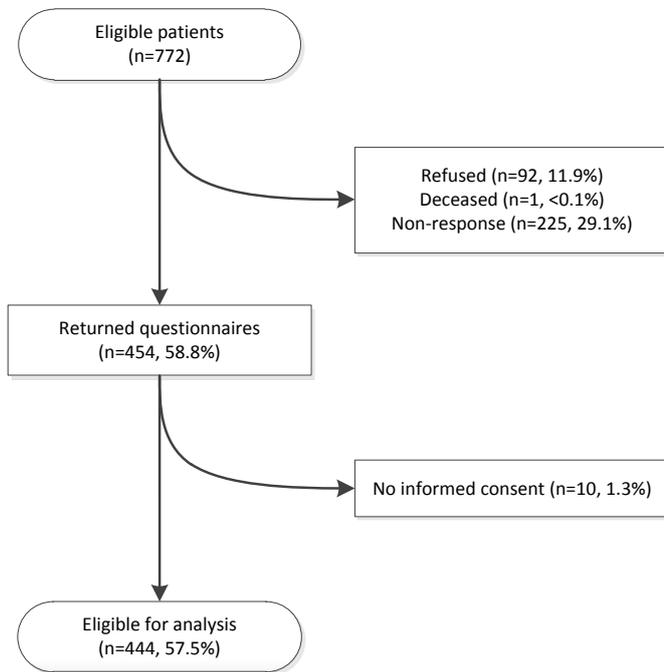
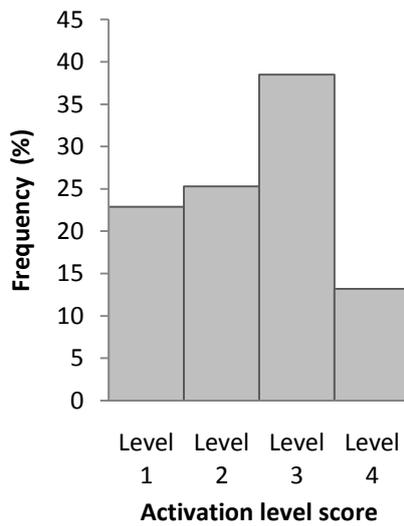


Figure 2 | Levels of activation



**Table 1 |** Baseline characteristics of the sample

<b>Socio-demographical characteristics</b>	<b>Patients (%) or mean <math>\pm</math> SD</b>
<b>Age (years) (n=444)</b>	68.3 $\pm$ 10.8
<b>Gender (male) (n=444)</b>	250 (56.3)
<b>Living situation (n=439)</b>	
Alone	111 (25.3)
With partner	276 (62.9)
With parents or children <sup>*</sup>	52 (11.8)
<b>Education (n=434)</b>	
Low <sup>†</sup>	217 (50.0)
Medium <sup>‡</sup>	158 (36.4)
High <sup>§</sup>	59 (13.6)
<b>Work (n=440)</b>	
Employed	84 (19.1)
Housewife/houseman	67 (15.2)
Retired	263 (59.8)
Disabled	15 (3.4)
Unemployed	11 (2.5)
<b>Ethnicity (n=440)</b>	
Dutch	424 (96.4)
Other	16 (3.6)
<b>Financial situation (n=428)</b>	
Comfortable	221 (51.6)
Just enough	167 (39.0)
Insufficient	40 (9.3)
<b>Smoking status (n=438)</b>	
No, never smoked	135 (30.8)
No, quit smoking	248 (56.6)
Yes, smoker	55 (12.6)
<b>Medical characteristics</b>	<b>Patients (%) or mean <math>\pm</math> SD</b>
<b>BMI (n=442)</b>	28.6 $\pm$ 4.2
<b>Years with diabetes (n=440)</b>	6.7 $\pm$ 4.4
<b>HbA<sub>1c</sub> (mmol/mol) (n=443)</b>	49.8 $\pm$ 10.0
<b>DM complications (no) (n=444)</b>	390 (87.8)
<b>Medication regimen (n=442)</b>	
None	204 (46.2)
Oral antidiabetic drug only	167 (37.8)
Oral antidiabetic drug and insulin	34 (7.7)
Insulin only	37 (8.4)
<b>Co-morbidities (n=444)</b>	
0	221 (49.8)
1	155 (34.9)
$\geq$ 2	68 (15.3)

<sup>\*</sup>) with or without partner; <sup>†</sup>) elementary education; <sup>‡</sup>) high school or middle-level applied education; <sup>§</sup>) higher professional or academic education.

**Table 2 |** Results of the questionnaires

<b>Variables</b>	<b>Mean</b>	<b>SD</b>	<b>Median</b>	<b>Observed range</b>	<b>Possible range</b>
<b>Activation (PAM)<sup>†</sup></b>	55.2	11.1	56.4	13.3 – 91.6	0 – 100
<b>Health status (SF-12)<sup>†</sup></b>	66.1	24.0	74.1	3.3 – 100.0	0 – 100
<b>Anxiety (HADS)<sup>‡</sup></b>	4.1	3.6	3	0 – 15	0 – 21
<b>Depression (HADS)<sup>‡</sup></b>	4.5	3.6	4	0 – 17	0 – 21
<b>Illness perception (B-IPQ)<sup>§</sup></b>	30.3	11.7	30	0 – 70	0 – 80
<b>Social support (MSPSS)<sup>  </sup></b>	62.6	15.1	64	12 – 84	12 – 84

<sup>†</sup>) Patient Activation Measure; <sup>†</sup>) Short Form-12; <sup>‡</sup>) Hospital Anxiety and Depression Scale;

<sup>§</sup>) Brief Illness Perception Questionnaire; <sup>||</sup>) Multidimensional Scale of Perceived Social Support.

**Table 3 |** Bivariate linear regression analysis on activation

Variables (n=423)	$\beta$	P
Age (years)	<0.01	0.992
Gender (Female vs. Male)	-0.68	0.533
<b>Living situation (RV<sup>*</sup>=Alone)</b>		
With partner	1.77	0.170
With children <sup>†</sup>	0.47	0.826
<b>Education (RV<sup>*</sup>=High<sup>‡</sup>)</b>		
Low <sup>§</sup>	-4.26	0.010
Medium <sup>  </sup>	-4.03	0.019
<b>Work (RV<sup>*</sup>=Disabled)</b>		
Working	6.46	0.039
Housewife/houseman	6.62	0.039
Retired	6.51	0.029
Unemployed	7.63	0.085
<b>Ethnicity (Other vs. Dutch)</b>	-6.70	0.018
<b>Financial situation (RV<sup>*</sup>=Comfortable)</b>		
Just enough	-4.57	<0.001
Insufficient	-6.13	0.001
<b>Smoking status (RV<sup>*</sup>=Never smoked)</b>		
No, quit smoking	0.04	0.974
Yes, smoker	-3.38	0.062
<b>BMI (kg/m<sup>2</sup>)</b>	-0.25	0.051
<b>Years with diabetes</b>	-0.11	0.365
<b>HbA<sub>1c</sub> (mmol/mol)</b>	-0.02	0.753
<b>DM related complications (Yes vs. No)</b>	-1.32	0.435
<b>Medication regimen (RV<sup>*</sup>=None)</b>		
Oral antidiabetic drug only	0.22	0.857
Oral antidiabetic drug and insulin	-0.99	0.638
Insulin only	0.99	0.631
<b>Co-morbidities (RV<sup>*</sup>=0)</b>		
1	-2.20	0.066
≥ 2	-3.82	0.015
<b>Health status (SF-12)<sup>¶</sup></b>	0.12	<0.001
<b>Anxiety (HADS<sup>#</sup>)</b>	-0.77	<0.001
<b>Depression (HADS<sup>#</sup>)</b>	-0.90	<0.001
<b>Illness perception (B-IPQ)<sup>**</sup></b>	-0.25	<0.001
<b>Social support (MSPSS)<sup>††</sup></b>	0.20	<0.001

\*) Reference Variable; †) with or without partner; ‡) higher professional or academic education; §) elementary education; ||) high school or middle-level applied education; ¶) Short Form-12; #) Hospital Anxiety and Depression Scale; \*\*) Brief Illness Perception Questionnaire; ††) Multidimensional Scale of Perceived Social Support.

**Table 4 |** Multiple linear regression analysis on activation

<b>Variables</b>	<b><math>\beta</math></b>	<b>P</b>
<b>(intercept)</b>	53.00	<0.001
<b>Depression (HADS)<sup>‡</sup></b>	-0.50	0.002
<b>Illness perception (IPQ)<sup>†</sup></b>	-0.15	0.003
<b>Social support (MSPSS)<sup>‡</sup></b>	0.14	<0.001

<sup>‡</sup>) Hospital Anxiety and Depression Scale;

<sup>†</sup>) Illness Perception Questionnaire;

<sup>‡</sup>) Multidimensional Scale of Perceived Social Support.

**Table 5 |** Bivariate logistic regression analysis on level one activation score

Variables (n=423)	$\beta$	P	OR	95% CI OR
<b>Age (years)</b>	-0.01	0.270	0.988	0.968 – 1.009
<b>Gender (Female vs. Male)</b>	0.14	0.545	1.150	0.732 – 1.807
<b>Living situation (RV<sup>†</sup>=Alone)</b>		0.020		
With partner	-0.72	0.006	0.498	0.294 – 0.813
With children <sup>†</sup>	-0.31	0.411	0.737	0.357 – 1.523
<b>Education (RV<sup>‡</sup>=High<sup>‡</sup>)</b>		0.048		
Low <sup>§</sup>	1.22	0.014	3.388	1.282 – 8.955
Medium <sup>  </sup>	1.10	0.028	3.018	1.128 – 8.075
<b>Work (RV<sup>†</sup>=Disabled)</b>		0.056		
Working	-1.43	0.014	0.239	0.076 – 0.746
Housewife/houseman	-1.21	0.039	0.298	0.94 – 0.943
Retired	-1.58	0.003	0.205	0.071 – 0.593
Unemployed	-1.64	0.081	0.194	0.031 – 1.221
<b>Ethnicity (Other vs. Dutch)</b>	1.09	0.036	2.970	1.076 – 8.196
<b>Financial situation (RV<sup>†</sup>=Comfortable)</b>		<0.001		
Just enough	1.04	<0.001	2.829	1.696 – 4.721
Insufficient	1.16	0.003	3.188	1.479 – 6.873
<b>Smoking status (RV<sup>†</sup>=Never smoked)</b>		0.502		
No, quit smoking	-0.04	0.893	0.965	0.574 – 1.621
Yes, smoker	0.36	0.331	1.433	0.694 – 2.958
<b>BMI (kg/m<sup>2</sup>)</b>	0.07	0.007	1.073	1.019 – 1.130
<b>Years with diabetes</b>	-0.01	0.653	0.988	0.938 – 1.041
<b>HbA<sub>1c</sub> (mmol/mol)</b>	-0.00	0.870	0.998	0.976 – 1.021
<b>DM related complications (Yes vs. No)</b>	0.03	0.943	1.025	0.517 – 2.034
<b>Medication regimen (RV<sup>†</sup>=None)</b>		0.994		
Oral antidiabetic drug only	-0.07	0.798	0.937	0.569 – 1.542
Oral antidiabetic drug and insulin	-0.09	0.848	0.916	0.374 – 2.241
Insulin only	-0.03	0.953	0.975	0.417 – 2.280
<b>Co-morbidities (RV<sup>†</sup>=0)</b>		0.162		
1	0.42	0.099	1.521	0.924 – 2.505
≥ 2	0.49	0.134	1.629	0.860 – 3.084
<b>Health status (SF-12)<sup>¶</sup></b>	-0.03	<0.001	0.974	0.965 – 0.983
<b>Anxiety (HADS)<sup>#</sup></b>	0.14	<0.001	1.153	1.083 – 1.226
<b>Depression (HADS)<sup>#</sup></b>	0.18	<0.001	1.200	1.125 – 1.280
<b>Illness perception (B-IPQ)<sup>**</sup></b>	0.05	<0.001	1.054	1.032 – 1.076
<b>Social support (MSPSS)<sup>††</sup></b>	-0.03	<0.001	0.972	0.957 – 0.986

<sup>†</sup>) Reference Variable; <sup>†</sup>) with or without partner; <sup>‡</sup>) higher professional or academic education;

<sup>§</sup>) elementary education; <sup>||</sup>) high school or middle-level applied education; <sup>¶</sup>) Short Form-12;

<sup>#</sup>) Hospital Anxiety and Depression Scale; <sup>\*\*</sup>) Brief Illness Perception Questionnaire;

<sup>††</sup>) Multidimensional Scale of Perceived Social Support.

**Table 6 |** Multiple logistic regression analysis on level one activation score

<b>Variables</b>	<b><math>\beta</math></b>	<b>P</b>	<b>OR</b>	<b>95% CI OR</b>
<b>(intercept)</b>	-0.15	0.841		
<b>Illness perception (B-IPQ)<sup>*)</sup></b>	0.04	0.004	1.035	1.011 – 1.060
<b>Health status (SF-12)<sup>†)</sup></b>	-0.02	0.003	0.984	0.973 – 0.994
<b>Social support (MSPSS)<sup>‡)</sup></b>	-0.02	0.022	0.981	0.966 – 0.997

<sup>\*)</sup> Brief Illness Perception Questionnaire; <sup>†)</sup> Short Form-12; <sup>‡)</sup> Multidimensional Scale of Perceived Social Support.

## 10. Dutch summary

**Titel:** Associaties tussen patiëntenkarakteristieken en activatie bij patiënten met diabetes type 2.

**Inleiding:** Patiënten met diabetes type 2 (DM-II) hebben vaardigheden, kennis en motivatie nodig om dagelijks hun ziekte te managen. Sommige patiëntengroepen hebben intensievere zelfmanagementbegeleiding nodig dan anderen. Momenteel is nog weinig bekend over de patiënten- en ziektegerelateerde karakteristieken van deze patiëntengroepen.

**Doel en onderzoeksvragen:** Met als doel het verder vergroten van zelfmanagementbegeleiding op maat, zijn de onderzoeksvragen: Welke patiënten- en ziektegerelateerde karakteristieken zijn geassocieerd met (slechte) zelf-managementcapaciteit bij volwassen patiënten met DM-II? Welke verhogen het risico om een slechte zelf-manager te zijn? Wat is de verdeling van zelfmanagementlevels bij patiënten met DM-II?

**Methode:** De studie had een kwantitatief, observationeel, explorerend, cross-sectioneel design, met patiënten met DM-II uit twee gezondheidscentra, met datacollectie middels vragenlijsten en dossieronderzoek. De afhankelijke variabele was zelfmanagementcapaciteit, gemeten als activatie met de Patiënt Activation Measure. De onafhankelijke variabelen waren zelf-gerapporteerde gezondheidstoestand, depressie, angst, ziekteperceptie, sociale steun, demografische variabelen en ziekte-specifieke variabelen. Data werden geanalyseerd met lineaire en logistische regressie.

**Resultaten:** Van de 444 participanten had 22,9% activatielevel één (laagste), 25,3% level twee, 38,5% level drie en 13,2% level vier. De belangrijkste verklarende variabelen na multivariate lineaire regressie waren depressie, sociale steun en ziekteperceptie, samen 14,1% van de variantie in activatie verklarend. Multipole logistische regressie liet zien dat een lage zelfgerapporteerde gezondheidstoestand, negatieve ziekteperceptie en weinig sociale steun het risico op slechte activatie vergroten.

**Conclusie:** Veel diabetici hebben nog begeleiding nodig om hun ziekte te managen. Daarnaast blijkt (slechte) activatie vooral geassocieerd te zijn met sociale steun, ziekteperceptie, depressie en zelfgerapporteerde gezondheidstoestand. Echter, variantie in activatie blijft voor het grootste gedeelte onduidelijk en het is nog steeds een uitdaging om patiënten te identificeren die meer zelfmanagementbegeleiding nodig hebben.

**Aanbevelingen:** Sociale steun, ziekteperceptie, depressie en zelf-gerapporteerde gezondheidstoestand verdienen aandacht in zorg voor diabetici. Longitudinaal onderzoek is nodig in verband met de beperkingen van het cross-sectionele design van deze studie.

**Trefwoorden:** Zelfmanagement, Activatie, Diabetes type 2, Cross-sectioneel

## 11. Abstract

**Title:** Associations between patient characteristics and activation in patients with type 2 diabetes.

**Background:** Patients with type 2 diabetes (DM-II) need skills, knowledge and motivation to self-manage their disease on a daily basis. Some patient subgroups need more intense self-management support than others. Little is known on the patient and disease characteristics of these subgroups.

**Aim and research questions:** To enhance targeting self-management support, three research questions were formulated. Which patient and disease characteristics are associated with self-management capacity in adult patients with DM-II? Which characteristics increase the risk of being a poor self-manager? What is the distribution of self-management capacity in patients with DM-II?

**Method:** The study had a quantitative, observational, explorative, cross-sectional design, including patients with DM-II from two primary health clinics. Data were collected with questionnaires and chart review. Dependent variable was self-management capacity, measured as activation with the Patient Activation Measure. Independent variables were self-reported health status, depression, anxiety, illness perception, social support, demographic variables and disease specific variables. Data were analysed through linear and logistic regression analysis.

**Results:** Of the 444 participants, 22.9% had activation level one (lowest), 25.3% level two, 38.5% level three and 13.2% level four. Key variables identified with multivariate linear regression were depression, social support and illness perception, explaining 14.1% of the variance in activation. Multiple logistic regression demonstrated that low self-reported health, negative illness perception and low social support increased the risk of poor activation (level one).

**Conclusion:** Many diabetic patients still need support in managing their disease. (Poor) activation is mainly associated with social support, illness perception, depression and self-reported health status. However, variance in activation remains unexplained for the greater part and it is still challenging to identify patients that need more support.

**Recommendations:** Social support, illness perception, depression and self-reported health deserve attention in diabetic care. Longitudinal research is indicated to overcome the limitations raised by this study's cross-sectional design.

**Keywords:** Self-management, Activation, Type 2 diabetes, Cross-sectional