Developments in patient activation of people with chronic illness and the impact of changes in self-reported health: results of a nationwide longitudinal study in The Netherlands

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ABSTRACT

Objective: To explore how patient activation, i.e. patients' perceived knowledge, skills and self-confidence to manage their health and healthcare, develops within chronically ill individuals over time, and to estimate the impact of self-rated health on this development.

Methods: Linear regression analyses and structural equation modeling were conducted using longitudinal data from 751 people with chronic disease(s). Patient activation was assessed by the patient activation measure; self-rated health was assessed by the SF-36 general health scale.

Results: Mean patient activation score at baseline was 60.6, and 18 months later 56.5. Baseline self-rated health had a positive, indirect effect on patient activation at 18 months. In addition, the change in self-rated health over one year (from baseline) was a significant predictor of patients' activation scores.

Conclusion: Patient activation is not a stable characteristic of people who have been chronically ill for years. Within individuals both increases and decreases occur, but at group level patient activation slightly decreases over time. This may (partly) be due to the deterioration of health that many people with chronic illness experience in course of time.

Practice implications: Clinical practitioners should assess the activation level of chronically ill patients regularly, especially when changes in health occur.

1. INTRODUCTION

Patient activation has become an important concept in chronic illness care. It has been defined as a combination of patients' knowledge, skills and self-confidence to manage their health and healthcare [1] and [2]. It has proven to be important for chronic illness care in several ways. First, knowing patients' level of activation enables health care providers to offer more tailored care, i.e. support and treatment that fit the personal goals and competencies of patients and meet their healthcare

needs [3]. Second, patients' activation level has proven to relate to preventive health behaviors and self-management (e.g. [2] and [4]). Patients on a higher activation level more often engage in healthy behaviors, more actively cope with their illness, make more efficient use of healthcare services and perform better self-care. Cross-sectional studies have demonstrated that chronically ill and primary care patients who are more actively involved in their care not only have better self-reported health outcomes (e.g. [5] and [6]), but also better clinical outcomes [2] and [7].

Patient activation has shown to be a changeable characteristic [3] and [8]. This is especially interesting because this might imply that patients' activation level could be increased. Results of the first intervention studies aimed at increasing patient activation levels are promising in this respect [8], [9] and [10]. However, little is known about the natural development of patient activation. Knowledge on how patient activation develops over time is important because it might contribute to the development of stepped care approaches and the delivery of care that is more tailored to the personal goals and needs for support of patients in different phases of their illness and lives. From the point of view of cost containment it is relevant to know how patient activation naturally develops, to decide whether intervening in a certain phase of the illness process may be useful, or even necessary, or not.

Whether patients' activation levels relate to their illness duration is not clear yet. Hendriks and colleagues found a significant association between illness duration and patient activation (as measured with the PAM; see Method section) among Dutch diabetic patients [11]. Patients who had been diagnosed less than 12 months ago as well as patients who had been diagnosed more than ten years ago had on average lower levels of activation than patients with an illness duration in between. It should be noted that this was a cross-sectional study, thus not providing information about the development of patient activation over time.

From health psychological theories, both positive and negative associations between illness duration and patient activation could be expected. Assuming that in general patients' knowledge about their disease and their skills to appropriately manage their illness will increase as a result of experience and contact with healthcare providers, one would expect the level of activation to increase with a longer illness duration. On the other hand, there is that third component of patient activation (besides knowledge and skills): self-confidence. Patients' confidence in their ability to adequately manage their illness might also grow because of their increased experience. But many chronic diseases are progressive in nature, which implies that sooner or later their severity and resulting disabilities will increase. Experiencing a deterioration of health, despite one's efforts to conduct adequate health behavior, may result in a loss of confidence in one's abilities, and consequently a decrease in activation level [12].

Empirical studies have consistently demonstrated a strong relationship between self-reported health and the level of patient activation. Rademakers and colleagues report that among their sample of medically diagnosed chronically ill about two thirds (65%) of the persons who rated their health as poor had a low activation level (level 1 or 2 based on PAM), whereas from the persons reporting their health as good, very good or excellent the great majority had a high activation level (level 3 or 4 based on

PAM) [13]. Self-rated health appeared to be more decisive for the level of patient activation than age, gender or education level, which was also the case in studies in the USA and Denmark [14] and [15]. Since these studies were all cross-sectional, it was impossible to establish cause and effect. Do patients experiencing a deterioration of health lose self-confidence and generate negative emotions that may affect their activation level? Or (and?) do patients with a higher activation level perform better self-management behaviors and communicate better with their health care professionals, resulting in better health outcomes?

By making use of a longitudinal design, the current study aims to provide more insight into the development of patient activation (without intervening on it) within chronically ill patients over time. In addition, we aim to gain more knowledge about the impact of chronically ill patients' self-rated health on their level of activation. Hence, we formulated the following research questions: (1) How does patient activation of people with chronic illness develop over time? And (2) Is the perception of one's health of predictive value for chronically ill patients' activation level over time?

2. METHOD

2.1. Design

Longitudinal study using survey data from people with chronic illness collected in three waves: at baseline (April 2011; $t0$), 12 months later ($t1$) and 18 months later ($t2$).

2.2. Sample

For the purpose of this study, we used data from people diagnosed with one (or more) chronic disease(s) who were participating in the National Panel of people with Chronic illness or Disability (NPCD), a nationwide prospective panel-study in The Netherlands [16] and [17]. NPCD was set up in 2005 to provide information about the experiences and consequences of living with chronic illness or disability from the patient's perspective.

Participants with chronic diseases are recruited from (random samples of) general practices in The Netherlands according to the following criteria: a diagnosis of a somatic chronic disease by a certified medical practitioner, aged ≥15 years, not being institutionalized, being aware of the diagnosis, not being terminally ill (life expectancy >6 months according to the GP), being mentally able to participate, and having sufficient mastery of the Dutch language (for more information, see [16]). Panel members fill in self-reported questionnaires at home twice a year, in April and October. NPCD is registered with the Dutch Data Protection Authority (registration no. 1283171); all data are collected and handled in accordance with the privacy protection guidelines of the Authority.

In April 2011, a survey was sent to 1669 panel members diagnosed with a chronic disease. A total of 1374 people completed this questionnaire (82%). Of these 1374

respondents, 939 also filled in the survey of April 2012 and 785 also responded to the survey of October 2012. The main reason for these lower numbers of respondents is that annually a quarter of all panel members with chronic disease(s) are replaced by new panel members, because they reached the maximum term of four years of participation in the panel-study. Response rates of the surveys of April 2012 and October 2012 were similar to the response rate of the April 2011 survey (both 83%).

A total of 751 panel members (55%) filled in all three questionnaires from which data were used for this study; they constitute the study sample.

2.3. Measurements

Patient activation was assessed at baseline (April 2011) and 18 months later (October 2012). Self-reported health was also assessed twice, at baseline and 12 months later (April 2012). Data on socio-demographic and disease characteristics of the patients were collected at inclusion in the panel-study.

2.4. Measuring instruments

Patient activation was measured by means of the Dutch validated version of the patient activation measure (PAM) [13] and [14]. The PAM consists of 13 items assessing knowledge, skills and confidence for self-management. All items have five answering options, ranging from 0 to 4: (1) 'disagree strongly', (2) 'disagree', (3) 'agree', (4) 'agree strongly' or (0) 'not applicable'. For calculating patients' activation scores, we followed the guidelines of Insignia Health [18]. In accordance with these guidelines, participants who answered less than seven questions or answered all items with 'disagree strongly' or 'agree strongly' were excluded, since they may not have responded in an accurate or truthful way. Based on these rules, we excluded, respectively, 9% and 7% of the total sample, leaving 681 (April 2011) and 701 persons (October 2012) for whom we could calculate a valid score. The mean score was calculated leaving out items that were deemed not applicable by the respondents, and then transformed into a standardized activation score ranging from 0 to 100 [18]. Higher scores indicate that patients are more activated to adopt and maintain healthy behaviors and self-management of their illness. Internal consistency of the PAM in this study was good; Cronbach's alpha was .85 at both measurements.

In addition to this continuous variable, we also computed a categorical variable reflecting patients' activation level. Based on their PAM scores, patients were divided into four progressively higher activation levels, which have been associated with distinct self-care and other health related behaviors [1] and [12]. At stage 1, people tend to be overwhelmed and do not consider an active role in managing their own health, they are rather passive recipients of care. At stage 2, people perceive they have an active role in managing their health, but they lack knowledge and confidence for self-management. At stage 3, people are beginning to take action but may still lack confidence and skills to adopt new behaviors. And finally, at stage 4, people have confidence and perform adequate behaviors but may have difficulty to maintain them under stressful circumstances.

Self-rated health was assessed by the validated Dutch version of the SF-36 general health scale [19], [20] and [21]. The scale consists of five items, each scored on a five-point response format (1–5). The mean score computed over the items is converted to a standardized score ranging from 0 to 100. Higher scores indicate perceptions of a better health in general. Internal consistency of the general health scale in this study was good; Cronbach's alpha was .81 at both measurements.

Illness duration was derived from the medical data provided by the general practitioners of the participants (with their permission). A variable was constructed by subtracting the year in which the (first) chronic disease had been diagnosed from the year of measurement (baseline), resulting in a continuous variable of the number of years post-diagnosis.

In addition, we included variables reflecting some *socio-demographic characteristics* of the patients: gender, age, education level, and household type. Education level was based on the highest level of education accomplished, and categorized in three categories: low (primary school or preparatory vocational training), intermediate (intermediate or advanced general education or intermediate vocational training) and high (high vocational education or university). Household type was treated as a dichotomous variable: living with or without a partner in the same household, irrespective of marital status.

The *type and number of chronic diseases* of the patients were included to provide some more information about our study sample. Type of disease was derived from patients' GP records and registered as ICPC codes [22]. The number of chronic diseases registered by the GP was categorized as one, two, and three or more chronic diseases.

2.5. Statistical analysis

Descriptive statistics were computed to provide information on the characteristics of the study sample. Univariate analyses were performed to check the assumed normal distributions of the data on patient activation and self-rated health and to describe chronically ill patients' activation scores (and level) and their self-rated health, both at baseline and follow-up. Differences in baseline activation scores and self-rated health and follow-up scores were tested by means of paired *t*-tests. The stability and changes in patient activation level were explored by computing frequencies of the patient activation level at *t*2 (18 months after baseline) for subgroups of patients with a different activation level at baseline.

Cross-sectional linear relationships (at baseline) between illness duration and self-rated health on the one hand and patient activation scores on the other were explored by computing Pearson's correlation coefficients. To detect a possible non-linear association between illness duration and patient activation, analysis of variance was performed. For this purpose, five patient groups with a different illness duration (see categorization in Table 1) were distinguished and the variance in the scores between and within these groups was compared. To account for age differences between the

five groups (age is related to illness duration), the analysis of variance was repeated with inclusion of age as a covariate.

[TABLE 1]

Next, we conducted linear regression analyses to estimate the longitudinal effects of (changes in) self-rated health on patient activation. In a first model, we estimated the effects of the initial patient activation score and self-rated health at baseline together with the effect of the difference in self-rated health over a year ($t1 - t0$) on patient activation 18 months later (dependent variable). In a second model, we added the socio-demographic characteristics of the patients (age, gender, education level as two dummy variables, household type) as independent variables to the first model. This was done to get an impression of the relative importance of these socio-demographic variables compared to the self-rated health variables for the prediction of patients' activation scores.

Finally, we estimated a model specifying the assumed causal pathways between self-rated health and patient activation by means of structural equation modeling. We first specified a model allowing free estimation of all possible effects of self-rated health and patient activation at baseline on patient activation 18 months later (see Fig. 1, Model 1). Since this model was saturated, it had a perfect fit. To check whether we could assume that patient activation does not impact on self-rated health – but rather that self-rated health impacts on patient activation – we estimated a second model not allowing patient activation at baseline to have an effect on self-rated health 12 months later (fixed at 0). The fit of this second model was compared to the first model by the chi-square statistic (model vs saturated) and the comparative fit index (CFI), whereas we also checked the standardized root mean squared residual (SRMR) to evaluate its absolute fit. CFI greater than .95 and SRMR smaller than .05 indicate a good model fit [23] and [24].

[FIGURE 1]

3. RESULTS

3.1. Sample characteristics

Table 1 contains the socio-demographic and disease characteristics of the study sample. The sample consisted of slightly more women than men. Mean age was 63 years. About one third had a low educational level and almost a quarter a high level of education. Three quarters were living with a partner in the same household. The most common chronic diseases of the respondents (not in table) were diabetes mellitus (21.8%), ischemic heart disease (12.3%), COPD (10.5%), asthma (10.3%) and osteoarthritis (9.6%). Half of the respondents had been diagnosed with more than one chronic disease.

3.2. Self-rated general health

First we checked the distribution of the self-rated health scores at t0 and t1 to assure that the use of parametric statistics and tests would be appropriate. Though Shapiro–Wilk tests were significant, histograms and Q–Q plots did not show large deviations from the assumed normal distribution and skewness and kurtosis measures were acceptable.

Patients had a mean general health score of 53.20 at baseline (Table 2), which is comparable to the mean score of Dutch citizens aged 75 and over in 2000, and considerably lower than the mean scores of about 70 found for men and women among the total Dutch population in 2000 [25]. One year later the average score was one point lower, 52.20. Comparing the individual scores of the respondents of whom both baseline and follow-up scores were available, a significant decrease in general health was found over one year (paired t-test; $P = .004$).

[TABLE 2]

3.3. Patient activation

Preliminary analyses showed that the distributions of the patient activation scores at both measuring moments resembled normality. Respondents had a mean PAM score at baseline of 60.63 and 56.47 18 months later (Table 2). At baseline, 37% of the respondents had a low activation level (level 1 or 2). Eighteen months later, almost half of the respondents had such a low level of patient activation. Comparing the individual scores of the respondents of whom both baseline and follow-up scores were available, a significant decrease over this 18-month period was found (paired t-test; $P < 001$). Explorative analyses of the patient activation scores within groups of respondents with specific chronic diseases (diabetes, ischemic heart diseases, COPD, asthma and osteoarthritis) did not show substantial differences in mean scores (and standard deviations) at baseline or 18 months later. In all five groups patient activation scores had been decreased after 18 months.

Table 3 shows that individual changes in patient activation level over a period of 18 months were very common. Only 41% of the respondents remained at the same activation level; 21% had a higher and 38% a lower activation level than their baseline level. Not only changes over one level (higher or lower) occurred, but also changes over more than one level.

[TABLE 3]

3.4. Cross-sectional relationships of patient activation with illness duration and self-rated health

Patient activation scores at baseline did not significantly correlate with illness duration (Pearson's $R = .01$, $P = .82$). To explore a possible non-linear association, we compared the PAM scores of respondents in five illness duration categories (categorized as in Table 1). Again, no significant association was found ($F(4, 659) =$

0.61, $P = .66$). Repeating the analysis of variance with inclusion of age as a covariate gave the same result.

Patient activation and self-rated health at baseline were positively associated (Pearson's $R = .35$, $P < 001$). Thus, patients who rated their general health as better, also had higher levels of patient activation.

3.5. Longitudinal effects of (changes in) self-rated health on patient activation

Table 4 contains the results of the linear regression analyses predicting patients' activation scores 18 months after the baseline assessment. Model 1 shows that – despite the many individual changes described above – the baseline activation score is still the best predictor (of the predictors included in the model) of the patient's activation score 18 months later. Furthermore, self-rated health is a significant predictor: patients who report better health at baseline have higher activation scores 18 months later. The individual change in self-rated health (from baseline over one year) does not significantly contribute to the prediction of patients' activation scores after 1.5 years. The three variables together explain about 20% of the variance in the patient activation scores at $t2$.

[TABLE 4]

Addition of the socio-demographic characteristics of the respondents (Model 2) does not change the previous results, except that the change in self-rated health now significantly contributes to the prediction of patient activation at 18 months as well. Furthermore, a high education level increases the chance of a higher patient activation score 18 months later, irrespective of one's activation score at baseline. Self-rated health is however more decisive than chronically ill patients' age, gender, education level and household type for patient activation.

3.6. Pathways between self-rated health and patient activation

Model 1 in Fig. 1 shows the estimated standardized coefficients of all possible pathways in which self-rated health and patient activation at baseline could impact on self-rated health at 12 months and patient activation at 18 months (saturated model). In accordance with the results of the regression analyses, it shows that patient activation at 18 months is partly determined by patient activation at baseline. However, the significant effect of baseline self-rated health on patient activation 18 months later, which we found in the regression analyses, now seems to be mainly an indirect effect via self-rated health at 12 months. Moreover, Model 1 (Fig. 1) shows that patient activation at baseline has a small but significant effect on self-rated health 12 months later. Testing a model without this effect (Table 5, Model 2a) results in a significant increase of the chi square.

[TABLE 5]

Based on the results of Model 1, we decided to test an alternative second model, assuming that self-rated health at baseline does not have a direct effect on patient

activation 18 months later (Model 2b). Table 5 shows that this does not lead to a significant increase of the chi square, suggesting that this model still fits the data very well. We additionally tested a model assuming that also self-rated health at 12 months does not have an effect on patient activation at 18 months (Model 3). Table 5 shows that this results in a significant increase of the chi square, suggesting that this third model could not be held.

Fig. 1 provides the standardized coefficients as well as the direct, indirect and total effects of Model 2b, which appears to be the best fitting model compared to the saturated model. It shows that the effect of self-rated health at baseline on patient activation at 18 months is an indirect effect.

4. DISCUSSION AND CONCLUSION

4.1. Discussion

This study has demonstrated that patient activation is not a stable characteristic of chronically ill patients. About one in five respondents was on a higher level of patient activation 1.5 years later, more than a third was on a lower level and about 40% remained at the same level. The baseline mean PAM score of 60.6 resembled the average score of 61.9 of the original American sample of persons aged 45 years and older [14], but the mean score after 1.5 years (56.5) was substantially lower. Results of other, cross-sectional Dutch studies show mean PAM scores varying between 56.9 among a general population sample [11] and 61.3 among chronically ill patients from the same NPCD panel-study as our sample [13].

Regarding the role of self-reported health, it was shown that chronically ill patients who reported better health at baseline had on average higher patient activation scores 1.5 years later, irrespective of their baseline activation score. Path analysis by means of structural equation modeling showed that self-rated health at baseline strongly relates to self-rated health one year later, which at its turn positively relates to patient activation six months later. Furthermore, patients whose self-rated health improved over one year (from baseline) had higher patient activation scores after 1.5 years. Unfortunately, self-rated health in general did not improve but deteriorated within our sample, which was not unexpected since most chronic diseases have a progressive nature and will become more complicating and disabling in many patients after several years.

In addition, we found some evidence that patients' activation level also impacts on their self-rated health. Patients who are more activated might perform better self-management, resulting in better health outcomes. However, we should keep in mind that patients' (self-rated) health is determined by many other factors as well.

Our findings suggest that chronically ill patients who have a certain level of patient activation will not always remain at that level or reach a higher level, but are also at risk for relapse. Knowledge and skills for self-management of the chronic disease may have developed during the course of illness, but may be perceived as insufficient or even inappropriate when confronted with new complications or

disabilities. This might affect patient's confidence or self-efficacy beliefs, resulting in a decrease in patient activation. Hibbard and Mahoney suggest that experiencing multiple failures in trying to manage chronic illness could bring about discouragement and disempowerment, which ultimately result in a passive approach to health. But they also emphasize the reverse: experiencing (even small) successes might gradually build confidence and positive emotions, which increase patient activation and ultimately lead to effective self-management [12].

4.2. Strengths and limitations

This study had a longitudinal design, which allowed us to estimate unidirectional associations between self-reported health and the development of patient activation within individuals. In this way we could demonstrate that self-reported health is a significant predictor of patient activation among people with chronic illness. This is not to say that we now know which mechanisms cause these effects. We have suggested that personal control or self-efficacy beliefs might be affected by the experience of poor health or health deterioration, and as such negatively influence patient activation. This should be further investigated.

Another issue is that although there were 1374 respondents in April 2011, our sample for this study consisted of only 751 persons (respondents on all three measurements). In the Method section we explained that the main reason for this lower number is that a substantial part of the panel members participating in April 2011 reached the maximum term of four years of participation between $t0$ and $t1$ (or $t2$) and were thus replaced by new panel members. Since these people did not decide for themselves to drop out, we believe that this could not have affected our results to a great extent. Testing the baseline scores of the PAM and the SF-36 general health scales between the study sample and the 'dropouts' did not reveal significant differences, suggesting that the two groups were at least at the start of the study comparable in this respect.

The participants we followed over 1.5 years had been included in the panel-study at a random moment in their disease process. We simply included a random selection of all patients subscribed to general practices who met our selection criteria, and time post-diagnosis was not a criterion. This resulted in a sample with a large variety in disease duration, but participants with a post-diagnosis duration of less than two years were scarce. It may be more informative to study a cohort of patients with chronic illness (or a specific chronic disease) right from the moment of diagnosis. In this way more insight could be gained into the development of patient activation during the first phase of chronic illness. In addition, following such a cohort for a longer period of time could increase our understanding of how patient activation relates to the course of illness within chronically ill patients.

Another limitation of our study was that self-reported health and patient activation were not assessed at the same measuring moments. Both were assessed at baseline, but self-reported health was reassessed after one year while patient activation was reassessed after 1.5 years. Self-reported health may have changed also in the last six months before the reassessment of patient activation, and we do not know whether and how it has changed. Our conclusion that a deterioration of perceived health

within chronically ill patients increases their chance of a lowered activation level might thus seem premature. However, given the progressive nature of most chronic diseases it is more plausible that participants' perceived health remained stable or further deteriorated over this last 6-months period than that it improved. We therefore believe that it is unlikely that we overestimated the effects of self-reported health on patient activation.

5. CONCLUSION

Patient activation is not a stable characteristic of people who have already been chronically ill for years. Within individuals both increases and decreases occur, but at group level patient activation slightly decreases over time. This may (partly) be due to the deterioration of health that many people with chronic illness experience in course of time.

5.1. Implications for clinical practice and research

Since patient activation is not a stable characteristic of people with chronic illness, it is important that clinical practitioners involved in chronic illness care not only assess patients' activation level in the first year(s) post-diagnosis, but continue assessing the activation level of their patients on a regular base, for instance each year and each time a significant change in health occurs and/or treatment needs to be adapted. This enables practitioners to tailor the care and self-management support they provide to the individual needs, preferences and competencies of their patients in certain phases of their illness process. Clinical practitioners should not assume that once a certain level of patient activation is reached, relapse will not be possible. Especially when patients perceive their health is deteriorating (or fluctuating), they may lose self-confidence and motivation to actively engage in the management of their illness. They may also need new knowledge and skills to adequately respond to their altered situation. Van Houtum and colleagues demonstrated that deterioration of self-perceived health within chronically ill patients relates to an increased need for self-management support [26]. It is therefore very important that clinicians be attentive to situations where patient activation is taxed.

Future research is needed to gain more insight in how patient activation of people with chronic illness develops over time. New studies should also focus on the first year(s) after a diagnosis of a chronic disease was established, since these years may be key to the development of patient activation within individuals. At the same time, studies in patient activation would benefit from a longer follow-up time with more measurements. With regard to intervention studies that aim to increase patients' activation levels, it is important that not only several post-intervention measurements will be done, but also more than one measurement prior to the intervention. Since patient activation of people with chronic illness already changes without purposefully intervening on it, several pre- and post-intervention measurements are necessary to be able to distinguish natural developments or fluctuations from changes caused by the intervention. Finally, more research is needed to detect disease-specific characteristics related to (the development of) patient activation. This could help to

design efficient, evidence-based innovations in the delivery of tailored care for people with chronic illness.

ACKNOWLEDGEMENTS

REFERENCES

[1]J.H. Hibbard, M. Tusler Assessing activation stage and employing a next steps approach to supporting patient self-management J Ambul Care Manage, 30 (2007), pp. 2–8

[2]J. Greene, J.H. Hibbard Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes J Gen Int Med, 27 (2011), pp. 520–526 http://dx.doi.org.proxy.library.uu.nl/10.1107/s11606-011-1931-2

[3]J.H. Hibbard, E.R. Mahoney, J. Stockard, M. Tusler Do increases in patient activation result in improved self-management behaviors Health Serv Res, 42 (2007), pp. 1443–1463

[4]K.J. Rask, D.C. Ziemer, S.A. Kohler, J.N. Hawley, F.J. Arinde, C. Barnes Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population Diab Educ, 25 (2009), pp. 622–630

[5]M. Von Korff, J. Gruman, J. Schaefer, S.J. Curry, E.H. Wagner Collaborative management of chronic illness Ann Intern Med, 127 (1997), pp. 1097–1102

[6]T. Bodemheimer, K. Lorig, H. Holman, K. Grumbach Patient self-management of chronic disease in primary care J Amer Med Assoc, 288 (2002), pp. 2469–2475

[7]C. Remmers, J.H. Hibbard, D.M. Mosen, M. Wagenfield, R.E. Hoye, C. Jones Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes J Ambul Care Manage, 32 (2009), pp. 320–327

[8]D. Frosch, D. Rincon, S. Ochoa, C. Mangione Activating seniors to improve chronic disease care: results from a pilot intervention study J Am Geriatr Soc, 58 (2010), pp. 1476–1503

[9]D. Deen, W.H. Lu, D. Rothstein, L. Santana, M.R. Gold Asking questions: the effect of a brief intervention in community health centers on patient activation Patient Educ Couns, 84 (2011), pp. 257–260

[10]M. Solomon, S.L. Wagner, J. Goes Effects of a web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial J Med Internet Res, 14 (2012), p. e32 http://dx.doi.org.proxy.library.uu.nl/10.2196/jmir.1924

[11]M. Hendriks, A.M. Plass, M. Heijmans, J. Rademakers Minder zelfmanagementvaardigheden, dus meer zorggebruik? [Less self-management competencies, more healthcare utilization?] De relatie tussen patiënt activatie van mensen met diabetes en hun zorggebruik, zorgkosten, ervaren met de zorg en diabetes gerelateerde klachtenNIVEL, Utrecht, the Netherlands (2013)

[12]J.H. Hibbard, E.R. Mahoney Toward a theory of patient and consumer activation Patient Educ Couns, 78 (2010), pp. 377–381

[13]J. Rademakers, J. Nijman, L. van der Hoek, M. Heijmans, M. Rijken Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13) BMC Public Health, 12 (2012), p. 577

[14]J.H. Hibbard, E.R. Mahoney, J. Stockard, M. Tusler Development and testing of a short form of the patient activation measure Health Serv Res, 40 (2005), p. 1918

[15]H. Terkildsen Maindal, I. Sokolowski, P. Versted Translation, adaptation and validation of the American short form Patient Activation Measure (PAM 13) in ad Danish version BMC Public Health, 9 (2009), p. 209

[16] M. Rijken, M. van Kerkhof, J. Dekker, F.G. Schellevis Comorbidity of chronic diseases effects of disease pairs on physical and mental functioning Qual Life Res, 14 (2005), pp. 45–55

[17] M. Rijken, P. Spreeuwenberg, J. Schippers, P.P. Groenewegen The importance of illness duration, age at diagnosis and the year of diagnosis for labour participation chances of people with chronic illness: results of a nationwide panel-study in the Netherlands BMC Public Health (2013) http://dx.doi.org.proxy.library.uu.nl/10.1186/1471-2458-13-803

[18] Insignia Health Patient activation measure (PAM) 13 license materials Insignia Health, Portland, Oregon (2010)

[19] J.E. Ware, C.D. Sherbourne The RAND-36 short-form health status survey: I. Conceptual framework and item selection Med Care, 30 (1992), pp. 473–481

[20] C.A. McHorney, J.E. Ware, J.F. Lu Sherbourne CD. The MOS 36-item short-form health survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups Med Care, 32 (1994), pp. 40–66

[21] K.I. van der Zee, R. Sanderman, J.W. Heyink, H. de Haes Psychometric qualities of the RAND 36-item health survey 1.0: a multidimensional measure of general health status Int J Behav Med, 3 (1996), pp. 104–122

[22] H. Lamberts, M. Wood ICPC: International classification of primary care Oxford University, Oxford (1987)

[23] B.M. Byrne Structural equation modeling with LISREL, PRELIS and SIMPLIS: basic concepts, applications and programming Lawrence Erlbaum Associates, Mahwah, NJ (1998)

[24] L.T. Hu, P.M. Bentler Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives Struct Equ Model, 6 (1999), pp. 1–55

[25] N. Hoeymans, H.S.J. Picavet Kwaliteit van leven gemeten met de SF-36 [Quality of life as assessed by the SF-36] Volksgezondheid Toekomst Verkenning, Nationaal Kompas VolksgezondheidRIVM, Bilthoven, The Netherlands (2005)

[26] L. van Houtum, M. Rijken, M. Heijmans, P. Groenewegen Self-management support needs of patients with chronic illness: do needs for support differ according to the course of illness? Patient Educ Couns (2013) http://dx.doi.org.proxy.library.uu.nl/10.1016/j.pec.2013.08.021

TABLES

Table 1. Socio-demographic and disease characteristics of the sample.

	N	n	%	Mean	SD
Gender	751				
Male		353	47.0		
Female		398	53.0		
Age (in years)	751			63.26	11.75
Education level	728				
Low		262	36.0		
Intermediate		294	40.4		
High		172	23.6		
Household type	746				
Without partner		183	24.5		
With partner		563	75.5		

	N	n	%	Mean	SD
Illness duration	733			10.85	9.41
Maximally 2 years		20	2.7		
2 to 5 years		192	26.2		
5 to 10 years		235	32.1		
10 to 20 years		213	29.1		
More than 20 years		73	10.0		
Number of chronic diseases	751				
One		376	50.1		
Two		220	29.3		
Three or more		155	20.7		

Table 2. Descriptive statistics of patient activation and self-rated general health..

|	Baseline				12 months later			
	N	Mean	SD		N	Mean	SD	
General health (0–100)	695	53.20	20.20		684	52.20	20.20	
	645[a]	53.93	20.20		645[a]	52.36	20.14	
	Baseline				18 months later			
	N	Mean	SD	%	N	Mean	SD	%
Patient activation (0–100)	681	60.63	15.23		701	56.47	13.09	
Level 1				18.4				22.3
Level 2				18.6				26.5
Level 3				32.2				31.5
Level 4				30.8				19.7
	643[b]	60.53	15.11		643[b]	56.40	12.80	
Level 1				18.5				22.1
Level 2				18.7				27.2
Level 3				32.5				31.3
Level 4				30.3				19.4

[a] Only respondents for whom both scores (baseline and 12 months later) were available.
[b] Only respondents for whom both scores (baseline and 18 months later) were available.

Table 3. Changes in patient activation level ($N = 643$).

Baseline	18 months later	
Level 1 ($n = 119$; 18.5%)	→ Level 1:	52.9%
	→ Level 2:	24.4%
	→ Level 3:	18.5%
	→ Level 4:	4.2%
Level 2 ($n = 120$; 18.7%)	→ Level 1:	27.5%
	→ Level 2:	37.5%
	→ Level 3:	28.3%
	→ Level 4:	6.7%
Level 3 ($n = 209$; 32.5%)	→ Level 1:	13.9%
	→ Level 2:	28.7%
	→ Level 3:	39.2%
	→ Level 4:	18.2%
	→ Level 2:	21.0%
	→ Level 3:	32.3%
	→ Level 4:	37.9%

Model 1: saturated model
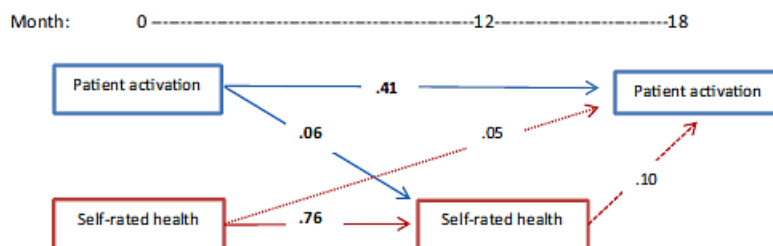
Coefficients in bold reflect they reached significance, p <.05

Standardized effects (P-values) on patient activation at 18 months

	Direct effect	Indirect effect	Total effect
Patient activation t0	.41 (<.001)	.01 (.20)	.41 (<.001)
Self-rated health t0	.05 (.38)	.07 (.10)	.13 (.001)
Self-rated health t1	.10 (.10)	-	.10 (.10)

Model 2b: alternative model assuming no direct effect of self-rated health at baseline on patient activation 18 months later
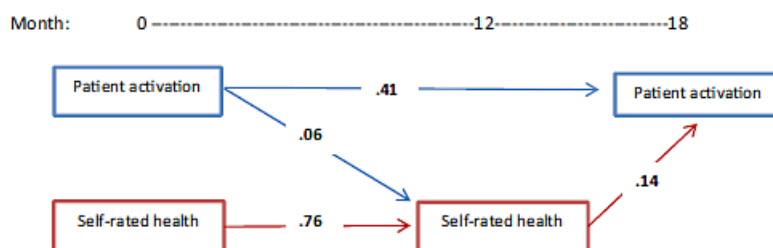
Coefficients in bold reflect they reached significance, p <.05

Standardized effects (P-values) on patient activation at 18 months

	Direct effect	Indirect effect	Total effect
Patient activation t0	.41 (<.001)	.01 (.08)	.42 (<.001)
Self-rated health t0	-	.10 (<.001)	.10 (<.001)
Self-rated health t1	.14 (<.001)	-	.14 (<.001)

Fig. 1. Effects of self-rated health and patient activation of chronically ill patients at baseline on self-rated health 12 months later and patient activation 18 months later (standardized coefficients; *N* = 561).

Table 4

Effects of baseline patient activation score ($t0$), self-rated health ($t0$) and change in self-rated health ($t1 - t0$) on patient activation score 18 months later ($t2$), without (Model 1) and with (Model 2) socio-demographic characteristics of the patients included as predictor variables.

	Patient activation score 18 months later ($t2$)			
	Model 1 ($N=593$)		Model 2 ($N=593$)	
	Beta	P	Beta	P
Patient activation score baseline ($t0$)	.39	<.001	.39	<.001
General health baseline ($t0$)	.16	<.001	.15	<.001
Change in general health ($t1 - t0$)	.07	.063	.08	.043
Age			−.05	.172
Gender: female			−.04	.299
Education level: intermediate			−.04	.295
Education level: high			.08	.046
Household type: with partner			.02	.556
R square		.22		.23
Adjusted R square		.21		.22
R square change				.02

Table 5. Measures of fit of Models 1, 2a, 2b and 3 ($N = 561$).

	Chi[b]	df	P	CFI[a]	SRMR[b]
turated) model	0	0		1	0
Model 2a (vs saturated)	4.080	1	.04	.995	.015
Model 2b (vs saturated)	0.760	1	.38	1.000	.005
Model 3 (vs saturated)	12.949	2	.002	0.984	.045

[a] CFI = comparative fit index.
[b] SRMR = standardized root mean squared residual.