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Patient perception, preference and participation

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 [1,2]. 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. [2,4]). 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. [5,6]), but also better clinical outcomes [2,7].

Patient activation has shown to be a changeable characteristic [3,8]. 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 [8–10]. 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

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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 [14,15]. 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; *t*0), 12 months later (*t*1) and 18 months later (*t*2).

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 [16,17]. 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) [13,14]. 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