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Research Information

Does patient activation predict the course of type 2 diabetes? A longitudinal study

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ABSTRACT

Objective: To examine whether patient activation is predictive of the course of diabetes over a three year period among patients with and without diabetes.
Methods: Longitudinal analyses utilized electronic health record data from 2011 to 2014. We examined how the patient activation measure (PAM) was predictive of 2014 diabetes-related outcomes among patients with diabetes (n = 10,071); pre-diabetes (n = 1804); and neither diabetes nor pre-diabetes (n = 46,402). Outcomes were clinical indicators (blood pressure, cholesterol, and trigylcerides), costly utilization, and progression from no diabetes to pre-diabetes or diabetes.
Results: Higher PAM level predicted better clinical indicator control in patients with diabetes. In patients with pre-diabetes, PAM level predicted better clinical indicator control, and those in the highest level of PAM in 2011 had lower odds of having a hospitalization compared to those in the lowest level. In patients without diabetes or pre-diabetes in 2011, higher PAM level was associated with lower odds of developing pre-diabetes.
Conclusions: More activated patients with diabetes and pre-diabetes had better outcomes than less activated patients. More activated patients without diabetes or pre-diabetes were less likely to develop pre-diabetes over a three year period.
Practice implications: Strategies to improve patient activation may be useful to help curb the diabetes epidemic.

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1. Introduction

Type 2 diabetes is an enormous public health challenge. In 2014, the CDC estimated that 29.1 million people in the United States had type 2 diabetes, 28% of whom were undiagnosed [1]. They further estimated that 86 million people had pre-diabetes, almost all of whom (90%) were undiagnosed. In the same year, the total estimated cost of type 2 diabetes, including costs of lost wages and medical costs, was estimated at $245 million per year. Both prevalence of diabetes and incidence of new type 2 diabetes diagnosis increased dramatically since between 1990 and 2008, and has continued to increase through 2012 among vulnerable populations (lower income adults, and Hispanic and African American adults) and younger adults [2].

Out of control type 2 diabetes can result in damage to blood vessels and nerves that can have a wide variety of consequences. These include diabetic retinopathy due to damage of blood vessels in the retina, neuropathies due to damage to the blood vessels that supply the nerves of the hands and feet, and damage to blood vessels in the kidneys resulting in kidney disease and kidney failure [3–7]. These consequences of out-of-control diabetes may lead to extreme disability and the need for medical interventions such as amputations and ocular surgeries [3,7].

In addition to medical consequences that are directly related to diabetes, patients with diabetes often suffer from comorbid health problems such as cardiovascular disease or depression [8,9]. For example, patients with type 2 diabetes are more than 1.5 times more likely to suffer from depression compared to those without type 2 diabetes, and patients with type 2 diabetes who were also depressed were more than twice as likely to die within a three year

period than patients with type 2 diabetes who were not depressed [10,11] Thus, the total burden of illness goes beyond what is reflected in the diabetes prevalence rates alone.

As health care delivery systems take on more responsibility for the health of their patient populations [12,13], finding ways to slow the progression of disease is a high priority. Part of that challenge is understanding who is most at risk for disease progression, and knowing how to effectively intervene with these patients.

Prior research has shown that patients' knowledge, skill, and confidence for managing their health and health care, often referred to as patient activation, is positively related to a wide range of health outcomes, including control of hemoglobin A1c among patients with diabetes [14–16]. Those who are less activated have more limited self-management skills, and are more vulnerable to health declines. This vulnerability was shown in a recent study that found that patients with lower activation levels, as measured by the patient activation measure (PAM), had 21–31% higher odds of developing a new chronic condition, including diabetes, in the following 1–3 years, as compared to more activated patients[17].

In this current study, we seek to build on this prior research and explore the extent to which a patient's activation level is related to the progression and control of diabetes, both among those with diabetes and pre-diabetes, and for those without diabetes how much activation level is related to developing diabetes. Although, there has been research using the PAM to predict outcomes among those already diagnosed with diabetes, we do not believe studies have yet looked at how patient activation predict the development of pre-diabetes and diabetes in a large clinical population. Additionally, no studies to our knowledge have examined how patient activation predicts diabetes progression specifically within a population with pre-diabetes as opposed to a general population.

1.1. What is patient activation and how does it differ from other related concepts?

The terms patient engagement and patient activation are frequently confused. The term patient engagement is often used to denote quite different concepts, ranging from proactive patient health behaviors to the interventions intended to improve patient behaviors [18–20]. Given the breadth of definitions, there have been several recent efforts to more concretely define it, which have not been consistent in their conceptualizations [18,21–23]. There is far less debate about the definition of patient activation. Activation, which is internal to the individual, emphasizes patients' willingness and ability to take independent actions to manage their health and care [24]. Patients who are more activated understand their own role in the care process and have the knowledge, skill, and confidence to manage their health and health care.

There are other constructs that are also related to patient activation. Self-efficacy is a closely related construct. Self-efficacy is included within the concept of activation, and the patient activation measure (PAM) includes several self-efficacy items. Internal locus of control is another related construct. Research shows that patient activation is positively correlated with internal locus of control ($r = 0.66$) [25]. However, activation is broader than just a sense of control or empowerment, as it also includes a sense of competence and self-assessed knowledge to inform action.

Because patients who are less activated are less likely to engage in healthy behaviors, preventive behaviors, or disease specific self-management behaviors, it is likely that they are more vulnerable to disease development and progression [26–28]. In this study, we build on the previous research on patient activation to specifically examine the following three research questions: 1) Is the PAM related to health outcomes three years later in patients with diabetes? 2) Is the PAM related to health outcomes and the development of diabetes among patients with pre-diabetes three years later? And 3) Is PAM level related to the future development of pre-diabetes and diabetes among patients without diabetes? We hypothesize that higher PAM levels will be associated with better health outcomes and lower likelihood of developing diabetes and pre-diabetes over time.

2. Methods

This study examines the extent to which 2011 patient activation levels are related to health outcomes three years later for three groups of patients, those categorized as having diabetes, pre-diabetes, or neither in 2011. It was conducted in collaboration with Fairview Health Services, a large not-for-profit health care system in Minnesota that is a Pioneer Accountable Care Organization. Since 2010, Fairview has routinely collected the PAM across its 44 primary care clinics.

This study protocol was approved by Human Subjects Committees at George Washington University, the University of Oregon, and the University of Minnesota.

2.1. Study population

To be included in this study, Fairview patients had to have been at least 45 years of age in 2011 and had to have had a primary care visit in 2011 in which the PAM was collected. Additionally, patients had to have had at least one office visit in 2014. For examining health outcomes in patients with diabetes, patients had to have had either a diagnosis of diabetes in 2011 or an HbA1c in 2011 of at least 6.5% (48 mmol/mol) (n = 10,071). For the analyses examining health outcomes and development of diabetes in patients with pre-diabetes, patients had to have had an HbA1c in 2011 between 5.7 and 6.5% (39 mmol/mol–48 mmol/mol) and no diabetes diagnosis in 2011(n = 1804) [29]. For the analyses examining the development of pre-diabetes and diabetes in patients without diabetes, patients had to have no diabetes diagnosis in 2011 and if there was an HbA1c result in 2011, it had to be less than 5.7% (39 mmol/mol) (n = 46,402).

2.2. Variables

2.2.1. Independent variable

Patient activation measured in 2011 was the key independent variable in all our analyses. It was measured using the PAM, an interval level, uni-dimensional, Guttman-like scale with strong psychometric properties [30,31]. The PAM is a latent construct, assessing an individual's self-concept as a self-manager of their health and health care. PAM items include statements about confidence, beliefs, knowledge, and skills about managing one's health and health care (e.g. "I know how to prevent problems with my health," "I am confident that I can tell a doctor my concerns, even when he or she does not ask."). Patients respond to the 13 items with degrees of agreement or disagreement, forming a 0–100 scale. Patients are then categorized into four levels of activation which have been previously validated, representing progression from a passive care recipient (level one) to a patient in great control of his or her own health (level four) [30]. Patients of PAM level one had a raw PAM score of 47.0 or lower. Those of PAM level two had a score between 47.1 and 55. 1. Level three included scores between 55.2 and 72.4. Finally, level four included scores of 72.5 or higher. The PAM has been translated into 28 different languages, the reliability and validity of several of those translations has been confirmed in peer reviewed publications, indicating that the concept and the measurement is valid across language and culture [32–37].