Focus on functioning in person-centered nurse-led diabetes care

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Associations between patient activation for self-management, diabetes distress and glycemic control in patients with type 2 diabetes: a cross-sectional study

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ABSTRACT

Aim

Patients with type 2 diabetes (DM2) are increasingly expected to self-manage their condition to achieve optimal glycemic control, which may be difficult due to influencing factors like diabetes distress. The aim of this study was to explore the associations between patient activation for self-management, diabetes distress and glycemic control.

Methods

In a cross-sectional study in 352 primary care patients with diabetes type 2, patient activation and diabetes distress were assessed using the Patient Activation Measure and Problem Areas in Diabetes scale, respectively. Spearman's rho and Mann-Whitney U test were used to explore associations and differences between groups, respectively. Hierarchical regression analyses were performed to analyze associations between patient activation, diabetes distress and glycemic control, corrected for patient characteristics and health-related factors.

Results

Poor glycemic control was associated with low patient activation levels and diabetes distress, corrected for the effects of blood glucose-lowering medication. Explained variance was 29.7%.

Conclusion

For optimal glycemic control, a biopsychosocial care approach is recommended in which healthcare providers, in particular nurses pay attention to blood glucose-lowering medication, patient activation for self-management, and diabetes distress.

INTRODUCTION

Type 2 diabetes mellitus (DM2) is one of the most prevalent chronic conditions worldwide and has been recognized as a major health challenge [1]. The age-adjusted comparative prevalence (95% confidence interval) of diabetes among adults aged 20–79 years in Europe was 6.3% (4.9–9.2%) in 2019 and is expected to rise to 7.8% (6.0–10.8%) in 2045 [2]. In response to the rising prevalence and growing burden of chronic disease, the chronic care model (CCM) was developed [3]. The CCM is person-centered in nature and considers biomedical and psychosocial needs and preferences of patients to be the starting point for care delivery. The aim of this model is to improve functional and clinical outcomes [3] through an interaction between an informed and activated patient and a prepared and proactive practice team [4]. In diabetes care, glycosylated hemoglobin (HbA1c), reflecting the average blood glucose for the last 2 to 3 months, is a well-known health indicator of glycemic control. To achieve good glycemic control and prevent diabetes-related complications, such as cardiovascular diseases, retinopathy, nephropathy, and neuropathy [1], patients with DM2 are expected to self-manage their condition by adopting a healthy lifestyle and adhering to treatment [5]. However, some patients may not be able to self-manage their chronic condition adequately [6].

Self-management refers to an individual's ability to manage the symptoms, treatments, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition [7]. Support of self-management is a key element of person-centered care as reflected by the CCM and is currently most often provided by nurses [8]. The ability to self-manage can be assessed with the Patient Activation Measure (PAM-13) [9]. This validated scale measures knowledge, skills, and confidence in managing one's health and segments patients into 1 out of 4 levels of activation. Patients with the lowest activation scores are passive recipients of care and believe that their healthcare providers are in charge of their health. Patients with the highest activation scores actually engage in recommended health behavior and take action to improve their health [10]. The PAM-13 has been used widely as a tool for optimizing person-centered care [11].

Patient activation levels are closely linked to self-management behavior [12]. From the perspective of diabetes care, self-management behavior includes a healthy diet, physical activity, blood glucose self-monitoring, and foot care. In contrast with patients with higher activation scores, patients with lower scores experience barriers to perform self-management adequately due to lack of knowledge and confidence to engage in self-management behavior [13]. Previous research demonstrated that self-management interventions, performed by healthcare professionals, led to small improvements in self-management behavior in patients [12] and health outcomes [14]. However, results of those interventions directed at glycemic control (HbA1c) were mixed [15]. The reduction in HbA1c levels was mostly found in participants with poor glycemic control [12,16].

Psychosocial health outcomes and patient factors influencing psychosocial health must also be considered as relevant factors in diabetes care delivery, even when

glycemic control is optimal [17]. From that perspective, the emotional side of diabetes and its management has received increasing attention in recent years [17]. Psychosocial distress in diabetes has been conceptualized as diabetes distress and refers to the 'negative emotional or affective experience resulting from the challenge of living with the demands of diabetes' [18]. A meta-analysis showed an overall prevalence of diabetes distress in people with DM2 of 36% [95% confidence interval 31; 41] [19]. Diabetes distress has been recognized as a barrier to optimal emotional well-being and self-management, leading to poor glycemic control [20]. International guidelines advocate routine screening for psychosocial problems in diabetes [5,21]. The validated Problem Areas in Diabetes (PAID) scale has therefore been recommended and is used widely [18].

Aim of the study

Whereas the impact of both patient activation for self-management and diabetes distress on glycemic control has been demonstrated independently, little is known about their combined impact on glycemic control. The aim of this study was to fill this gap in knowledge. These new insights may support nurses' interventions to meet patients' needs and to improve health outcomes by prioritizing elements of self-management support. Research questions were:

1. Which patient factors are associated with glycemic control?
2. What are the associations between patient activation for self-management, diabetes distress and glycemic control, controlled for patient characteristics and health-related patient factors?

METHODS

Study design

To answer the research questions, a cross-sectional study was conducted. Data were collected between January 2020 and September 2020 in several general practices in the Northeast region of The Netherlands.

Setting and participants

In Dutch primary care setting, diabetes care is predominantly provided by a POH-S (in Dutch: Praktijk Ondersteuner Huisarts-Somatiek). This position is often performed by registered nurses who are educated at a bachelor's level at a University of Applied Sciences or specialized doctors' assistants, who have completed a secondary vocational training. Both professionals followed an additional specialized training in protocolized diabetes care to provide diabetes care according to the guidelines from the Dutch College of Primary Care Physicians [22] and chronic disease management programs [23]. The chronic care program for DM2 includes an average of 4 monitoring visits per year, consisting of biomedical check-ups (weight, blood pressure, blood

glucose, and cholesterol levels, complications) and assessments of psychosocial factors, such as well-being, lifestyle issues, and adherence to medication.

Patients were eligible for inclusion in this study when they were diagnosed with DM2 for at least 1 year, were aged 18 years or older, spoke Dutch, and were able to give written informed consent for linking their medical and questionnaire data. All patients with DM2 who visited the general practice during the inclusion period were informed about the study and were asked to participate. Patients who did not return their questionnaires within 2 weeks were reminded by phone once.

Data collection

The following patient factors were collected: patient characteristics, patient activation for self-management, diabetes distress, and health-related factors:

- Patient characteristics were assessed by means of a self-reported questionnaire that included questions on gender, age, marital status, health literacy score, socioeconomic status, employment status, education level, alcohol use, and smoking status. Health status was assessed by the EuroQol-visual analogue scale (EQ-VAS) [24]. Scores range between 0 - 100, with higher scores representing better health status.
- Patient activation for self-management was assessed using the validated Dutch translated 13-item Patient Activation Measure (PAM-13). Items are scored on a 4-point Likert scale ranging from totally disagree (1) to totally agree (4). A not applicable option is also available. Scores between 0-100 were calculated using the Insignia Health PAM-13 scoring table [25] and reflect 4 activation levels ranging from low to high. According to Insignia Health and taking into account practical use of activation levels, the PAM levels for this study were dichotomized into low PAM (score 0-55.1) and high PAM (score 55.2-100).
- Diabetes distress was assessed using the validated 5-item Problem Areas in Diabetes (PAID-5) questionnaire [26]. This questionnaire assesses fear, depressive symptoms, concerns about the future, and demands of living with diabetes. Items are scored on a 5-point response scale ranging from 0 (no problems) to 4 (serious problems). The total score ranges from 0 to 20. A PAID score of ≥ 8 indicates diabetes distress [26].
- Health-related factors were extracted from the patient's electronic health record and include HbA1c in mmol/mol, duration of DM2 in years; Body Mass Index (BMI) in kg/m2; number of diabetes complications registered, such as retinopathy, neuropathy, nephropathy, hypertension, and vascular diseases; total number of medication prescriptions, including type of blood glucose-lowering medication (oral medication and/or insulin and/or glucagon-like peptide-1 (GLP-1) receptor agonist; and 1-year health services use during the past year and registered as insured care.

Statistical analyses

Statistical analyses were performed using SPSS 23.0 software (SPSS inc.). Descriptive analyses were undertaken to provide frequencies, percentages (%), means, standard

deviations (SD), medians, confident intervals (CI), and interquartile ranges (IQR; p25; p75). Missing data were not imputed.

Bivariate analyses were performed to explore associations between patient factors as described above and glycemic control (HbA1c in mmol/mol). Because the distribution of data was skewed, Spearman's rho was used to explore associations between continuous patient factors and HbA1c. A Mann-Whitney U test was used to explore differences between groups.

A hierarchical multivariable regression was performed to analyze the association between patient activation for self-management (PAM), diabetes distress (PAID) and glycemic control (HbA1c), controlled for patient characteristics and health-related factors. First, patient factors associated with HbA1c ($p \leq 0.1$) were entered into the regression analysis. Next, patient factors with the highest p-values were removed manually one at a time until all p-values in the regression model were ≤ 0.1. Interaction terms were explored. Residuals were checked for a normal distribution.

Ethical considerations

The current study was approved by the local Medical Ethics Committee (METC no. 2019/688), declaring that the study did not fall under the scope of the Medical Research Involving Human Subjects Act. Informed consent was obtained from all participants.

RESULTS

Of the 615 invited patients, a total of 352 patients (57%) participated in this study. Median (IQR) age was 71 (64.0;75.0) years. A total of 55% of the participants were male, and 40% had a low education level. A total of 73% of the participants used oral blood glucose-lowering medication, of which 20% of the participants used insulin or GLP-1 as well. The median (IQR) BMI of the sample was 30 (27.0;34.2) kg/m2 and median (IQR) duration of DM was 9 years (5.0;14). The median (IQR) HbA1c was 53 (47.0;61.0) mmol/mol. The median (IQR) PAM score was 58.1 (51.0;72.5) which reflect a high level of activation. A total of 149 participants (42%) reported low levels of activation for self-management. The median (IQR) PAID score was 2.0 (0.0;5.0). A total of 49 participants (14%) reported diabetes distress **(Table 6.1)**.

Bivariate analysis showed that patients with higher HbA1c values had lower education levels ($p=0.013$) and used more medication ($p=0.062$), including more oral blood glucose-lowering medication ($p<0.001$) and insulin or GLP-1 ($p< 0.001$). They had lower PAM scores ($p=0.015$), higher PAID scores ($p<0.001$), a longer duration of DM2 ($p< 0.001$), a higher BMI ($p=0.097$), and they used health services more often ($p=0.001$) than patients with lower HbA1c values.

For the regression analysis, first patient factors associated ($p \leq 0.1$) with HbA1c were entered into the regression analysis, resulting in Model 1 (**Table 6.2**). Explained variance ($R^{2*}100\%$) was 28.9%. Next, patient factors with the highest p-values were

Table 6.1* Participants characteristics (n=352)

Characteristics (n valid observations)	n (%)
Gender *Male*	193 (54.8)
Age *(352)* median (IQR)	71.0 (64.0;75.0)
Marital status *Living alone*	112 (32.0)
Health literacy score 0-12 *(352)* median (IQR)	10.0 (8.0;12.0)
Limited health literacy (score < 9)	107 (30.4)
Self-management activation (PAM) score 0-100 *(352)* median (IQR)	58.1 (51.0;72.5)
PAM low	149 (42.3)
PAM high	203 (57.7)
Alcohol use	14 (4.7)
Current smoker	50 (14.3)
Deprived environment	55 (15.6)
Employment status *Unemployed or retired*	275 (78.8)
Education level *No or low education*	138 (40.1)
Duration DM2 in years *(352)* median (IQR)	9.0 (5.0;14.0)
HbA1c in mmol/mol *(352)* median (IQR)	53.0 (47.0;61.0)
BMI in kg/m2 *(352)* median (IQR)	30.1 (27.0;34.2)
Number of complications *(352)* median (IQR)	1.0 (1.0;2.0)
Amount of medication *(349)* median (IQR)	7.0 (4.0;11.0)
Oral blood glucose-lowering medication	256 (72.7)
Insuline and/or GLP-1	69 (19.6)
PAID score 0-20 *(351)* median (IQR)	2.0 (0.0;5.0)
Diabetes distress (PAID score ≥ 8)	49 (14.0)
Health status *(352)* score 0-100 median (IQR)	70.0 (65.0;80.0)
Health services use in 1 year *(352)* median (IQR)	13.0 (8.0;21.0)

*Part of this table is also presented in Chapter 5 (Table 5.1)
IQR: Inter Quartile Range (25th percentile; 75th percentile). PAM: Patient Activation Measure. DM2: type 2 diabetes; BMI: Body Mass Index. GLP-1: Glucagon-like peptide-1 receptor agonist. PAID: Problem Areas In Diabetes.

Table 6.2 Patient factors associated with HbA1c (n=352)

	Unstandardized Coefficients		95 % CI			
	B	**Std. Error**	**Lower bound**	**Upper bound**	**p***	*Adjusted R^2*
Model 1						0.289
Education level	-1.413	1.098	-3.573	0.746	0.199	
Duration DM2 in years	0.063	0.072	-0.078	0.204	0.383	
BMI (kg/m2)	-0.012	0.096	-0.201	0.177	0.901	
Amount of medication	-0.256	0.126	-0.503	-0.009	0.043	
Oral blood glucose-lowering medication	8.329	1.169	6.029	10.628	<0.001	
Insuline or GLP_1	8.534	1.438	5.705	11.364	<0.001	
Health services use 1 year	0.043	0.054	-0.064	0.150	0.429	
PAID score	0.283	0.148	-0.009	0.575	0.057	
PAM score	-0.072	0.033	-0.138	-0.007	0.030	
Constant	52.739	4.250	44.379	61.098	<0.001	
Model 2						0.297
Oral blood glucose-lowering medication	8.441	1.137	6.205	10.677	<0.001	*0.172*
Insuline or GLP-1	8.557	1.301	5.998	11.115	<0.001	*0.101*
PAID score	0.268	0.144	-0.016	0.552	0.065	*0.016*
PAM score	-0.072	0.032	-0.135	-0.010	0.023	*0.007*
Constant	50.852	2.250	46.426	55.278	<0.001	

*Results from hierarchical multivariable regression. CI = Confidence Interval, R2= Explained variance. DM2: type 2 diabetes; BMI: Body Mass Index; GLP-1: glucagon-like peptide-1 receptor agonist.; PAM: Patient Activation Measure. PAID: Problem Areas In Diabetes.

Model 1: Patient factors univariately associated with HbA1c. Patient factors with the highest p-values were removed manually step-by-step until all p values in the regression model were ≤0.1, resulting in model 2. Model 2 provides insight in the explained variance of each variable in HbA1c and a total amount of explained variance (R2*100%) of 29.7%, of which blood glucose-lowering medication (oral and insulin/GLP-1) contributed a total of 27%.

removed manually one at a time until all p-values in the regression model were ≤ 0.1, resulting in Model 2. Model 2 gives insight into the explained variance of each variable in HbA1c and the total explained variance of 29.7%, to which blood glucose-lowering medication contributed most (27.3%). Residuals were normally distributed. No interaction effects were found.

DISCUSSION

This study showed that poor glycemic control was associated with low levels of patient activation for self-management and diabetes distress, corrected for the effects of blood glucose-lowering medication. Use of blood glucose-lowering medication, patient activation levels, and diabetes distress explained a total of 29.7% of the variance in HbA1c.

Patient factors associated with glycemic control

The findings of this study highlight the association of both biomedical and psychosocial factors with the health outcome glycemic control. Blood glucose-lowering medication can be classified as a biomedical factor, and patient activation for self-management and diabetes distress can be classified as psychosocial factors.

Blood glucose-lowering medication (oral, insulin, GLP-1) largely explained the variance in glycemic control (27.3%), which is not surprising. After all, medication aims to lower the blood glucose level in order to make patients feel better physically and to prevent complications. In the current study, median glycemic control was optimal, as reflected by a 'normal' HbA1c (53 mmol/mol) of the sample.

Patient activation for self-management explained only a small, but significant part of the variance in glycemic control (0.7%) in the current study. The effect of self-management on HbA1c has been recognized previously [13]. An explanation for this association may be that patients with low activation levels experienced barriers (e.g., lack of skills, knowledge, and/or motivation) to perform adequate self-management and therefore had poor glycemic control. In the current study, almost half of the sample had low activation levels, slightly more than previously reported [27]. This high proportion can be explained by the older age of the sample, high BMI, lower education level, more limited health literacy, and lower health status [28]. Support of self-management is an important task for nurses in providing chronic care [29]. This study confirmed an association between low patient activation for self-management and higher HbA1c levels as previously noticed [30]. Since patient activation for self-management can predict the course of DM2 [30], an adequate activation level may be required to maintain good glycemic control. This knowledge argues for a bio-psychosocial care approach in which healthcare providers, in particular nurses address patient activation for self-management in progressive conditions such as DM2. Interventions for each level of activation have been developed for this purpose [25].

For example, patients with lower activation levels may need more or adjusted education compared with patients with higher levels of activation.

Diabetes distress also explained only a small but significant part of the variance in HbA1c (1.6%). The prevalence of diabetes distress in the current study (14.0%) was lower than previously reported [19]. This finding may be explained by the older age of the sample, given that younger age is independently associated with diabetes distress [31]. While the effect of diabetes distress on glycemic control has been previously noticed [19], the direction of this association is however less clear and can be interpreted in a twofold way. On the one hand, HbA1c may be a determinant for diabetes distress, indicating that worries about complications due to elevated HbA1c may increase diabetes distress [32]. When HbA1c decreases, for instance, as a result of medication use, worries and fears about complications may diminish. On the other hand, diabetes distress may be a determinant for HbA1c, indicating that elevated levels of distress may increase HbA1c. This direction has been previously noticed; reductions in distress were significantly associated with improved self-management and improved glycemic control [33]. The explanation for this association may be that the emotional burden of daily demands of managing diabetes (i.e., demands of adherence to a healthy lifestyle and treatment regimen) may prevent patients from actually performing adequate self-management [34], which consequently may lead to worse glycemic control. These findings support the view that healthcare providers should be aware of the emotional side of having diabetes and its management [35]. Whether diabetes distress is determined by rising HbA1c or low activation levels, a biopsychosocial perspective of healthcare providers, in particular nurses is recommended in diabetes care. From this perspective, healthcare providers should be aware of diabetes distress and consider additional patient factors influencing glycemic control.

In the current study, interaction terms were explored as well. Associations between both patient activation for self-management and diabetes distress in relation to glycemic control were demonstrated; however, no interaction effects were found. In contrast, another study did find an interaction effect between diabetes distress and health literacy [34]; the latter was found to be highly associated with patient activation for self-management [27]. These outcomes emphasize the complexity of relationships between patient factors.

This study has some limitations. First, self-reported questionnaires might have led to socially desirable answers on the PAM and PAID questionnaires, resulting in an underestimation of the strength of the associations and their influence on glycemic control. Furthermore, a total of 43% of patients did not respond to the invitation (including a reminder) to participate. Reasons for non-responding remained largely unknown. Some patients forgot to fill out the questionnaires or withdrew without explanation. Given the prevalence of limited health literacy (34%) in the study, patients may have found it too difficult to complete all the questionnaires themselves. Finally, due to the cross-sectional design, no conclusions could be drawn on the cause and direction of associations.

One of the strengths of this study is the large and varied sample of patients with DM2 in general practices. Validated measurements were used and revealed data about

patient activation for self-management and diabetes distress. These insights may be useful for nurses in providing person-centered care and the measurements may be used as practical tools in providing self-management support. As recently recognized by a qualitative study [36], the findings in this study argue for a biopsychosocial care approach by healthcare providers, in particular nurses involved in diabetes care.

Relevance for clinical practice

To achieve and maintain optimal glycemic control, healthcare providers, in particular nurses who play a key role in self-management support, should pay attention to blood glucose-lowering medication, patient activation levels for self-management, and diabetes distress. From this biopsychosocial viewpoint, nurses should explore whether diabetes distress is determined by rising HbA1c or low levels of patient activation for self-management. Given that DM2 is a progressive chronic condition, nurses should already start to focus on patient activation for self-management when glycemic control is still optimal. Future studies are needed to explore additional factors influencing glycemic control.

CONCLUSION

Poor glycemic control was associated with low patient activation for self-management and diabetes distress. When corrected for the effects of blood glucose-lowering medication, a total of almost 30% of the variance in HbA1c could be explained. To optimize glycemic control, a biopsychosocial care approach is recommended in which nurses address medication use, patient activation for self-management, and diabetes distress. Additional patient factors should be considered as they may influence glycemic control.

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