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Research paper

When knowing is not enough: Emotional distress and depression reduce the positive effects of health literacy on diabetes self-management

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ABSTRACT

Objectives: Adequate self-management activities are important predictors of diabetes outcomes. As diabetes literacy and self-efficacy are strong predictors of diabetes self-care, self-management education programs focus essentially on these factors. This study investigated whether emotional distress or depression moderates the relation between health literacy, self-efficacy and diabetes self-care behaviors. **Methods:** 128 people with type 2 diabetes were recruited in hospitals, through general practitioners and via a diabetes website, and completed a questionnaire assessing health literacy, self-efficacy, diabetes-related distress, depression and self-care behaviors.

Results: Multiple regression analysis confirms that health literacy and self-efficacy significantly predict reported self-care behaviors. Additional regression analyses reveal that distress or depression do not predict self-care behaviors directly, but moderate the effect of health literacy, which has a weaker impact in patients experiencing distress or depression. In contrast, distress and depression do not moderate the effect of self-efficacy on diabetes self-care behaviors.

Conclusion: Emotional distress, whether related to diabetes or not, prevents patients from acting on their competence to perform adequate self-management behaviors.

Practice implications: Diabetes Professionals should pay more attention to the patients' affective state and its influence on self-care. Psychological support should be integrated in the care for people suffering from type 2 diabetes.

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1. Introduction

Early diagnosis and appropriate management of type 2 diabetes significantly increase the chances of preventing harmful and costly complications. Therefore, the care for patients with diabetes focuses strongly on disease management. Because managing diabetes requires extensive self-care, the capacities of patients to manage their own illness and care process are considered to be a key determinant of treatment outcomes [1]. The practice guide of the American Association of Diabetes Educators [2] specifies seven self-care behaviors that are essential for people with diabetes: (a) healthy eating, (b) being active, (c) blood glucose monitoring, (d) taking medication, (e) problem

solving (e.g. when there is an obstacle to dietary compliance), (f) healthy coping (e.g. speaking with friends or playing music to deal with stress), and (g) changing behaviors that increase the risk of developing diabetes complications (such as smoking or alcohol consumption).

The patient's adherence to the above-mentioned self-care behaviors is critical to achieve better glycemic control and, thereby, avoid complications associated to a poor diabetes control [3,4]. Understanding the factors that influence adherence is therefore of utmost importance. As appears from the literature, a patient's adherence to the treatment is affected by several factors, both at the patient level (e.g. health literacy, self-efficacy) and at the provider or service level (e.g. organization of health services, communication skills). The current paper focuses on three individual factors that may impact on self-care behaviors for diabetes, i.e., health literacy, self-efficacy, and emotional distress. Recent studies have demonstrated the impact of these factors on self-care behaviors separately, but to our knowledge, none has examined the potential interactions between them. This study

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investigates whether emotional distress can moderate the relationship between health literacy or self-efficacy on diabetes self-care behaviors.

Health literacy is defined as “a person’s knowledge and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.” [5,6]. It is well established that a low level of health literacy leads to poorer health outcomes, greater use of health care services, poorer adherence to medication, and poorer self-care behaviors [7]. As the treatment of diabetes requires the patient to seek information, take health-related decisions, and understand medical instructions, health literacy is highly relevant for diabetes treatment [8]. Lower levels of health literacy have indeed been associated with poorer knowledge about diabetes and poor glycemic control [5,6], which increases the risk of developing diabetes-related complications like retinopathy [9–11].

Self-efficacy is defined as a person’s beliefs about his or her capacities to complete tasks and reach goals. These beliefs, whether justified or not, influence a person’s choices, goals, and motivation to engage in behavior to reach these goals [12,13]. The concept of self-efficacy has been integrated in several theoretical models that explain and predict health-related behaviors, such as the Protection Motivation Theory [14] and the Theory of Planned Behavior [15]. In the context of diabetes self-management, it was shown that a strong sense of self-efficacy is related to higher glycemic control and self-care behaviors [16] and to a better adherence to the medical treatment [17].

While health literacy and self-efficacy are cognitive constructs, the management of diabetes is also related to emotional factors. The fact of being diagnosed with diabetes can be a big challenge for the patient. In addition, the treatment of the illness requires a great adaptation, as the newly diagnosed patient has to learn to self-manage his(her) illness at all times and in all situations [9]. Therefore, patients with diabetes are likely to experience a range of emotions regarding their treatment and the possible risk of complications, such as feeling stressed or defeated by the disease, feeling it controls their life, worrying about their capacity to self-manage their diabetes, losing their motivation, avoiding tasks that could give negative feedback of their self-management capacity, and feeling alone to face the disease [9]. This range of emotions is referred to as “diabetes-related distress” [18]. The prevalence of distress is higher among patients who are treated with insulin injections [19] and among younger patients [20]. It has been demonstrated that emotional distress in diabetes is related to poorer adherence and poorer self-management [21], but it remains unclear whether distress is the cause or consequence of these outcomes. Patient who feel distressed are also less willing to perform self-care activities, which can lead to higher levels of glycated hemoglobin [22] and higher risk of mortality [23].

In addition to distress, diabetes patients are also vulnerable to develop clinical depression. Based on a meta-analysis, Anderson and co-workers [24] estimated that 31% of patients with diabetes had symptoms of depression and 11% major depression. In controlled studies indicated by these authors, the proportion of people who reported depression was twice as high in the diabetes group compared to the comparison group [24]. Three reasons may underlie this high prevalence: firstly, diabetes entails a number of restrictions and constraints, which may be a source of depression. Secondly, depressive people are more at risk for developing diabetes because of poor lifestyle habits (e.g., physical inactivity, high-fat diet, smoking, alcohol consumption, . . .) or metabolic disturbances [25]. Finally, the depression and diabetes may both be the effect of a third variable, notably overweight, as overweight

people are more at risk to develop both depression and diabetes [26].

Whereas the impact of health literacy, self-efficacy, emotional distress and depression on adherence to diabetes treatment have been demonstrated independently, no studies have been performed to date which considered these factors simultaneously. As a result, it is not known to what extent these cognitive and emotional processes interact. The present study attempts to fill this gap by investigating whether the impact of patients’ health literacy and self-efficacy beliefs on their self-care behaviors is moderated by diabetes-related distress and depression. Specifically, we hypothesized that distress and/or depression would attenuate/eliminate the positive effect of health literacy and self-efficacy on diabetes self-care behavior by preventing the patient from using his (her) cognitive resources to manage the disease and treatment.

2. Methods

2.1. Recruitment and data collection procedure

Participants were patients with Type 2 diabetes mellitus who were recruited from 7 different sources: two hospitals, two diabetes centers, two general practices, and the Belgian Diabetes Association. Only patients with Type 2 diabetes (80% of diabetes cases (27)) were included in the study.

Data collection was performed between August 2014 and March 2015 and involved the distribution of a questionnaire in two ways: (1) a paper version of the questionnaire was handed to the patients from the collaborating hospitals, diabetes centers, and general practices, to be completed at home and returned to the researchers in a pre-stamped envelope; (2) an online version of the questionnaire was made available via a web-link placed on the website of the Belgian Diabetes Association [27]. In total, 409 paper questionnaires were distributed: 197 in the two hospitals; 160 in the diabetes centers, and 52 in the general practices.

Ethical approval was obtained from the ethical committees of the participating hospitals (P2014/256). Each participant provided informed consent in writing.

2.2. Evaluation instruments

Self-care behaviors were assessed by means of the Diabetes Self-Management Questionnaire (DSMQ) [28], which contains 16 items in the form of self-management activities (e.g. *I do regular physical activity to achieve optimal blood sugar levels; I keep all doctors’ appointments recommended for my diabetes treatment*; etc.) to be scored on a 4-point Likert scale ranging between “does not apply to me” to “strongly applies to me”. The questionnaire yields scores on 4 sub-scales: “glucose management” (GM), “dietary control” (DC), “physical activity” (PA), and “health-care use” (HU), as well as a “sum scale” (SS). In this study, the questionnaire shows an acceptable level of internal consistency ($\alpha = 0.719$).

Two questionnaires were used to assess health literacy. General health literacy was measured via the 6-item version of the European Health Literacy Survey Questionnaire (HLS-EU-Q6) [29], which produces a mean score ranging from 1 to 4. Participants who score less than 2 are considered to have an insufficient level of health literacy; those who score between 2 and 3 have a limited level of health literacy; and those who score more than 3 are considered to be sufficiently health literate. The HLS-EU-Q6 shows very strong correlations with both the full version HLS-EU-Q47 and the 16-item shorter version HLS-EU-Q16 [30]. The internal consistency of this scale in our sample is adequate ($\alpha = 0.797$). Diabetes-specific health literacy was

assessed by the questionnaire developed by Ishikawa et al. [31], which measures functional (difficulties in reading the instructions or leaflets from hospitals and pharmacies), communicative (patients' extraction and communication of diabetes-related information since they were diagnosed with the disease) and critical (critical analysis of the information and used it to make decisions) health literacy related to diabetes via 11 items. The internal consistency of this scale ($\alpha = 0.852$) and of its sub-scales ($\alpha = 0.860$; $\alpha = 0.797$; $\alpha = 0.744$) in our sample is adequate. For the purpose of our study, and based on the PCA results (see Supplementary material), the combined score of general health literacy and diabetes-specific health literacy was used, which will be referred to as "health and diabetes literacy".

Self-efficacy beliefs were assessed using the 15-item version of the Diabetes Management Self-Efficacy Scale (DMSES) [32], which measures people's beliefs concerning their efficacy to perform self-care activities in 4 areas: specific nutrition and weight, general nutrition and medical treatment, physical exercise, and blood sugar control. An item related to general practitioner visits was added from the initial 20-item version. The final questionnaire is thus composed of 16 items. The internal consistency of the scale in the current sample was 0.864.

Diabetes-related distress was assessed by means of the Diabetes Distress Scale (DDS) [33], which measures patients' distress in four domains: emotional burden, physician-related distress, regimen-related distress, diabetes-related interpersonal distress. The 17 items of the questionnaire are rated on 6-point scale ranging from "not a problem", "mild problem" and "serious problem". The internal consistency coefficient for this scale in the current sample was very good ($\alpha = 0.933$) and good to very good for its sub-scales ($\alpha = 0.873$; $\alpha = 0.973$; $\alpha = 0.824$; $\alpha = 0.873$).

Depression was measured by the 13 item version of the Beck Depression Inventory (BDI), which is known to be a good instrument to detect major depression among people with diabetes [34]. The total score can vary between 0 and 39 and discriminates between minimal depression, mild depression, moderate depression, and severe depression. The internal consistency of the scale in the current sample was 0.864.

With the exception of the BDI, none of the selected questionnaires was available and validated in French. The DSMQ, the HLS-EU-Q6, the diabetes specific health literacy questionnaire, the DMSES, and the DDS were translated into French by a native speaker, using the back-translation method to validate and ensure the quality of the translation.

2.3. Statistical analyses

Principal component analyses (PCA) with Varimax rotation were performed to confirm the factorial construct validity of each of the translated questionnaires. The influence of health literacy, self-efficacy beliefs, diabetes-related distress and depression on diabetes self-care was tested via multiple linear regressions. A first multiple linear regression assessed the impact of health literacy and self-efficacy on diabetes self-care behaviors. To consider the moderating impact of distress on the relation between health literacy, self-efficacy and diabetes self-care behaviors, a second multiple regression analysis was performed. Additional multiple regression analyses, with the sub-scales of diabetes-related distress as moderators, are detailed in the Supplementary material. The independent variables were first centered in order to calculate the interaction terms. These interaction terms were then introduced in the regression as independent variables. All statistical analyses were performed with the IBM SPSS 22 software.

3. Results

3.1. Sample

In total, 128 patients participated in the study: 67 (52.3%) returned the paper questionnaire (16.4% of the questionnaires that had been distributed), and 61 (47.7%) completed the online questionnaire. Among those who completed the paper version, 38 (29.7%) were treated in one of the two hospitals, 12 (9.4%) in a diabetes center, and 17 (13.3%) by a general practitioner. Participants' characteristics are summarized in Table 1.

The means, standard deviations and internal consistency coefficient of the different scales and subscales resulting from the PCA are summarized in Table 2.

3.2. Impact of health literacy and self-efficacy on self-care behaviors

A first multiple regression analysis shows that, as predicted, the level of health and diabetes literacy combined and the patients' self-efficacy beliefs predict the reported self-care behaviors (Model 1, Table 3).

3.3. Moderating effect of diabetes-related distress and depression

3.3.1. Diabetes-related distress as a moderator

Model 2 in Table 3 shows the results of the multiple regression analysis with diabetes-related distress as a moderator of the effects of health and diabetes literacy and self-efficacy beliefs on self-care behaviors. The model is significant. As for Model 1, both health and diabetes literacy and self-efficacy predict diabetes self-care activities directly. Diabetes-related distress does not predict the

Table 1
Characteristics of the sample.

Sociodemographic variables	
Mean age	61.87 (SD = 12.27)
Gender	F: 47.6%/M: 52.4%
Number of years of schooling achieved	12.25 (SD = 3.08)
Education status	
No diploma	0.8%
Primary education	5.6%
Lower secondary education	15.3%
Upper secondary education	42.7%
Higher education (3 years)	20.2%
Higher education (≥ 5 years)	10.5%
Other	4.8%
Professional status	
Employed or self-employed	26%
Unemployed	36.2%
Retired	35.4%
Student	2.4%
Marital status	
Married	57.9%
Divorced	18.3%
Widowed	14.3%
Single	9.5%
Number of years with diabetes	12.64 (SD = 9.87)
Age of diagnosis	
After 40	65.6%
Between 30 and 39	13.3%
Between 20 and 29	3.9%
Before 20	6.2%
Missing	10.9%
Diabetes treatment	
Healthy lifestyle exclusively	3.2%
Oral medication	61.6%
Insulin injection	53.6%
Concerned by diabetes-related complications	30.6%

Table 2
Means, standard deviations and internal consistency coefficient of the different scales and subscales.

Scale	Mean	SD	α
Diabetes Self-Management Questionnaire (DSMQ)	2.09	0.420	0.719
Glucose management	2.26	0.78	0.706
Dietary control	1.92	0.76	0.587
Physical activity	1.63	0.82	0.568
Health-care use	2.58	0.58	0.441
Health Literacy	2.96	0.48	0.852
European Health Literacy Questionnaire (HLS-EU-Q6)	2.85	0.64	0.797
	9.8% inadequate HL (<2)		
	42.2% limited HL ([2;3])		
	48% sufficient HL (≥ 3)		
Diabetes-related health literacy [31]	3.01	0.52	0.824
Diabetes Management Self-efficacy Scale (DMSES)	2.75	0.75	0.915
Nutrition and physical activity	2.37	0.88	0.877
Medical treatment	3.25	0.73	0.734
Blood sugar	3.02	1.03	0.884
Diabetes-related distress (DDS)	2.48	1.14	0.933
Emotional burden	2.79	1.34	0.873
Physician-related distress	1.97	1.40	0.923
Regimen-related distress	2.44	1.17	0.824
Diabetes-related interpersonal distress	2.69	1.61	0.873
Depression (BDI)	6.63	5.766	0.864
	36.5% minimal dep (0–3)		
	29.8% mild dep (4–7)		
	20.2% moderate dep (8–15)		
	13.5% severe dep (16–39)		

Table 3
Regression and interaction analysis to predict reported diabetes self-care behaviors.

	R^2	β	t	p
Model 1	0.317			
Health literacy (HLS-EU-Q6 + Diabetes specific HL)		0.301	3.018	≤ 0.001
Self-efficacy		0.350	3.509	≤ 0.001
Model 2	0.380			≤ 0.001
Health literacy (HLS-EU-Q6 + Diabetes specific HL)		0.321	3.030	≤ 0.005
Self-efficacy		0.415	3.642	≤ 0.001
Distress		0.092	0.987	0.326
Health literacy*Distress		-0.256	-2.490	≤ 0.05
Self-efficacy*Distress		0.137	1.334	0.185
Model 3	0.402			≤ 0.001
Health literacy (HLS-EU-Q6 + Diabetes specific HL)		0.300	2.987	≤ 0.005
Self-efficacy		0.346	3.335	≤ 0.001
Depression		-0.089	-1.003	0.319
Health literacy*Depression		-0.322	-3.260	≤ 0.005
Self-efficacy*Depression		0.151	1.515	0.133

self-care activities directly, but the interaction of distress and health and diabetes literacy does: When the patient reports diabetes-related distress, the positive impact of health & diabetes literacy on self-care activities is significantly less important (Fig. 1). This moderating effect remains stable after controlling for professional and education status. It is also noted that diabetes-related distress does not significantly moderate the impact of self-efficacy on self-care (Fig. 2).

3.3.2. Depression as a moderator

Model 3 in Table 3 shows the results of the multiple regression analysis with depression as a moderator of the effect of health literacy and self-efficacy on self-care behaviors. The model is again significant. Similar to Models 1 and 2, health and diabetes literacy and self-efficacy both predict diabetes self-care activities, while depression does not predict these activities directly, but influences the effect of health literacy. When a patient with diabetes reports depression, the impact of health and diabetes literacy on self-care behaviors is significantly less important (Fig. 1). This moderating

effect remains stable after controlling for professional and education status. Again, the moderating impact of depression is only found for health literacy but not for the impact of self-efficacy on diabetes self-care (Fig. 2).

4. Discussion and conclusion

4.1. Discussion

This study investigated the moderating effect of diabetes-related distress and depression on the relationship between health literacy, self-efficacy and diabetes self-care behaviors. Diabetes-related distress and depression were shown to reduce the positive effect of health and diabetes literacy on self-care behaviors.

In our sample of 128 Type 2 diabetes patients, 44.1% presented limited to insufficient health literacy. This result is very similar to what is observed in the general Belgian population [29]. Among our participants, 17.5% and 11.7% reported moderate (≥ 8) and severe (≥ 14) depression respectively. These proportions do not

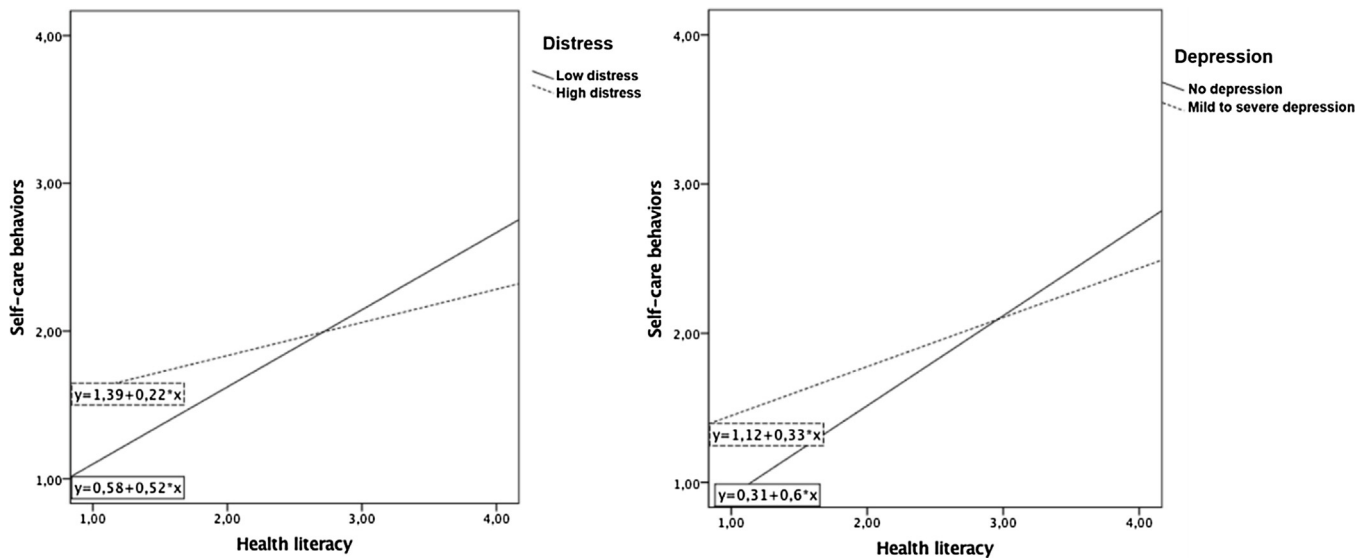


Fig. 1. Impact of health & diabetes literacy on self-care behaviors depending on diabetes-related distress or depression.

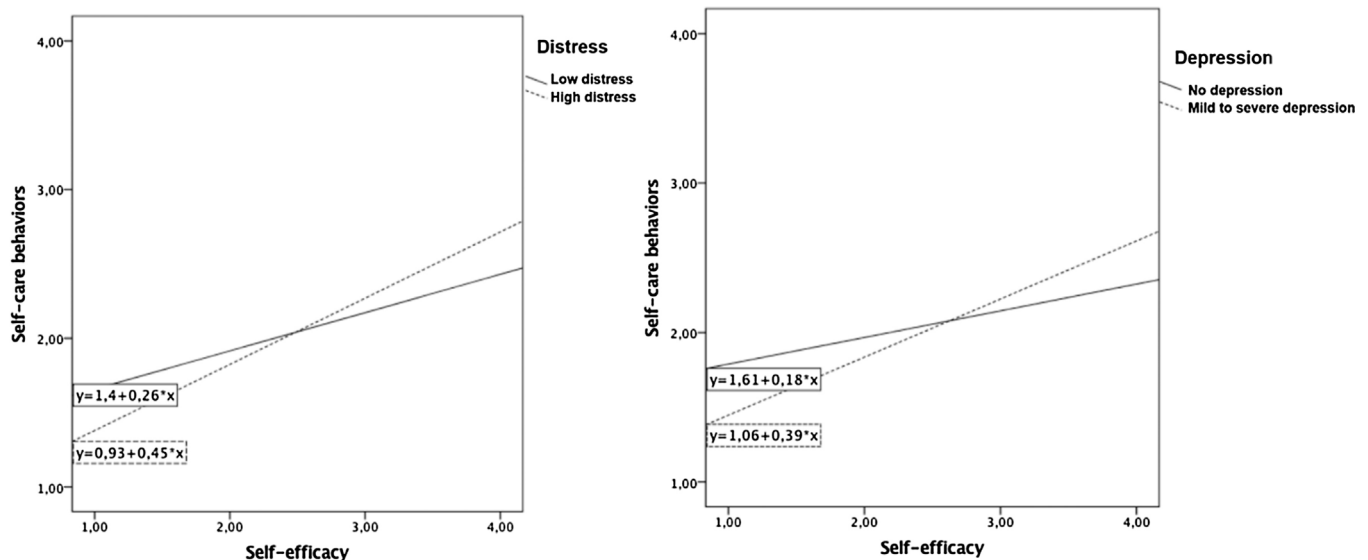


Fig. 2. Impact of self-efficacy on self-care behaviors depending on diabetes-related distress or depression.

differ much from what is usually found for adults with diabetes using the BDI [24]. In accordance with the literature [5,6,16,17], health literacy and self-efficacy significantly predicted the self-care behaviors reported by the patients, in the sense that patients with higher levels of health literacy and higher efficacy beliefs regarding diabetes self-management more often reported appropriate self-care behaviors. In our data, health literacy appears to be the strongest predictors of self-care behaviors.

Contrary to previous studies [21,22], diabetes-related distress and depression were not directly associated with poorer self-care behaviors in our sample. However, the interactions between diabetes-related distress and health literacy, as well as between depression and health literacy, significantly predicted self-care behaviors. When patients reported being depressed, their self-care activities were less influenced by the level of health literacy. The same was found for diabetes-related distress, whereby an interaction with health literacy was found for the emotional burden, physician-related distress and interpersonal distress. So, without having a direct impact, emotional distress (whether

clinical or subclinical) seems to reduce the positive effects of health literacy on self-care activities. For patients with severe depression, the general reduction of energy and loss of interest may prevent the use of health literacy resources to self-manage the disease correctly. With regard to the moderating impact of distress, the emotional burden and distress related to a lack of support by the doctor or relatives may also restrain the patient in the utilization of his/her health and diabetes literacy to perform adequate self-care behaviors.

It should be noted that a similar moderating effect of depression and diabetes-related distress was not found for self-efficacy. One explanation for this could be that self-efficacy is already more associated with emotional distress than the level of health literacy. According to Gonzalez, the link between diabetes-related distress and poor medication adherence can be explained by the lower level of self-efficacy. In this case, self-efficacy is represented as a mediator of the relationship between distress and self-care behaviors. In addition, Bandura [13] underlined that a low self-efficacy can increase the vulnerability to depression. As a

consequence of these potential links between self-efficacy, emotional distress and self-care behaviors, it is understandable that in our study the interaction was not significant.

While this study has produced important findings regarding the interaction between cognitive and emotional factors that influence self-care behavior of patients with diabetes, some limitations need to be recognized.

A first limitation concerns the representativeness of the sample. Among the 409 paper questionnaires distributed, only 67 were returned (16.4%). As the patients were invited to participate in a study on diabetes and emotional distress, it could be that those suffering from distress related to their diabetes were more willing to participate. In addition, the majority of type 2 diabetes included in this study were on medication, either by taking oral medication or by insulin injections. Only 3.2% were treating their diabetes exclusively through a healthy lifestyle. Therefore, the results may not entirely reflect the reality of Type 2 diabetes patients who are not treated with medication.

A second limitation refers to the self-report nature of the collected data. As the participants estimated the quality of their own self-care behaviors, this measure may have been subject to social desirability bias. A further limitation concerns the cross-sectional design of our study. Due to this design it is not possible to determine the direction of the observed relationships. Prospective studies are necessary to further illuminate the direction of these relationships.

4.2. Conclusion

As diabetes treatment requires extensive self-care activities, the patient's capacities to manage his/her own illness is a key determinant of treatment outcomes. These capacities can be influenced by cognitive and affective factors. This study showed that the levels of health literacy (i.e. the person's capacity to access, understand, assess and apply health-related information) and self-efficacy have a positive impact on reported diabetes self-care behaviors. However, for health literacy, this positive effect disappears when the patient suffers from depression or diabetes-related distress. These results offer new evidence of the role of cognitive and emotional factors in diabetes self-management. Further research involving longitudinal designs should be conducted to learn more about the links between these variables and identify the main causes of depression and distress among diabetes patients, such as repeated frustration toward the treatment, lack of diabetes self-efficacy, coping strategies, exhaustion of personal resources to deal with the disease, fear of complications, etc.

4.3. Practice implications

Patients with sufficient health literacy tend to adhere better to their treatment. However, when patients are experiencing depression and/or diabetes-related distress, the positive impact of health literacy is reduced. This suggests that the emotional burden interferes with the cognitive resources that are required for adequate diabetes self-management. In view of the high prevalence of depressive symptoms amongst patients with diabetes – depression is twice as prevalent among diabetes patients than in the overall population – health professionals should acknowledge the debilitating impact of this condition on cognitive capacities, and realize that patients who have enough knowledge to self-manage their diabetes but who suffer from emotional distress are less able to put this knowledge into practice. A cross-sectional study of Hajos et al. [35] indicated that the physicians do not always appreciate properly patients' perceptions of the disease and their emotional status. In the light of these elements, diabetes services should focus on depression and distress screening and

integrate more psychological support to diabetes self-management education. A systematic literature review [36] showed that, currently, very few diabetes interventions focus on both physical and mental health improvement. It seems reasonable to suggest that an emotional intelligence training, in addition to classical diabetes education, could help patients to deal with diabetes-related distress. Emotional intelligence trainings aim to improve people capacities to identify, understand, express, regulate and use their own emotions and emotions from the others [37]. These trainings have proved their effectiveness in improving psychological well-being (such as stress and distress) and self-reported physical health in general population [38,39] and also among type 2 diabetes patients [40,41]. Teaching patients to deal with difficult emotions such as diabetes-related distress may help them to preserve their cognitive resources to self-manage their disease and treatment.

Conflict of interest

The four authors have no conflict of interest.

Author contributions

LS and FD collected the data and performed the data analysis. LS wrote the article manuscript.

SVDB and MM supervised the data collection and analysis, and contributed to writing and editing the manuscript.

All authors have approved the final article.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.pec.2017.08.006>.

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