

Postprint Version	1.0
Journal website	http://linkinghub.elsevier.com/retrieve/pii/S0738-3991(10)00381-2
Pubmed link	http://www.ncbi.nlm.nih.gov/pubmed/20655164
DOI	10.1016/j.pec.2010.06.019

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Opinions of patients with type 2 diabetes about responsibility, setting targets and willingness to take medication. A cross-sectional survey

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ABSTRACT

Objective: To assess opinions and their determinants of patients with type 2 diabetes about responsibility for managing their diabetes, setting treatment targets and willingness taking medication.

Methods: Questionnaire survey carried out in general practices and outpatient clinics across the Netherlands. **Outcomes:** opinions about responsibility, targets and medication. Multinomial logistic regression analysis.

Results: Data of 994 consecutive persons were analysed (mean age 65 years; 54% males). Of these 62% agreed to take responsibility for their diabetes. In the opinion of 89% the setting of targets should be by or in cooperation with their physician or nurse and 40% were willing to take tablets until all targets were attained. Patients who perceived dysfunction by barriers to activity did not agree to take responsibility (OR 3.68; 1.65–8.19). Patients with complications preferred to set targets in cooperation with their physician or nurse (OR 1.98; 1.03–3.80). Males were more willing to take tablets until all targets were attained (OR 1.62; 1.17–2.25).

Conclusion: Not all patients want to take responsibility for their diabetes or taking all necessary tablets, especially those with barriers to activity or complications.

Practice implications: Doctors and nurses should ask for patients' opinions about responsibility and treatment goals before starting education.

1. INTRODUCTION

Lifestyle change remains a central part of treatment of type 2 diabetes (T2DM) [1]. The most important choices affecting the health of a person are made by that person, not by health professionals [2]. Therefore, the patient's view on self-management is considered essential in diabetes care [3] and [4]. Self-efficacy is necessary to improve self-management and self-care and has been associated with improved clinical outcomes [5] and [6]. There is debate on the responsibilities of healthcare professionals and patients regarding health counselling and lifestyle change [7]. The general trend has been a gradual replacement of authoritarian and instructive care traditions by patient-centered methods aiming at patient empowerment [8]. Self-management of T2DM has become increasingly the patient's responsibility [9]. On the other hand, diabetes care has been standardized through protocols, guidelines and clinical targets [10]. The treatment

targets for HbA1c, blood pressure, and lipids are set at stricter levels worldwide, implicating that patients need to take more medication [1]. A variety of factors have been associated with control of blood glucose and cardiovascular risk factors, suggesting that a one-size-fits-all approach to multiple risk factor reduction efforts may not result in attainment of targets [11]. Therefore, individual targets should be tailored for each patient, but to our knowledge negotiating targets with people with T2DM does not routinely occur [12] and [13]. Little is known about the opinions of people with diabetes on relevant topics such as taking responsibility for managing diabetes, the preferred person to determine their personal treatment targets and the willingness to take medication to attain these targets [4]. Therefore, this survey aims to study the association between peoples' opinions about taking responsibility, setting treatment targets and willingness to take medication on the one hand and patients' characteristics and health related quality of life on the other.

2. METHODS

In 2007 80 general practitioners (GPs) and 13 endocrinologists across the Netherlands participated in this study. Over a 3-month period, consecutive patients with T2DM were recruited by their own care providers during regular visits at the practice or outpatient clinic. Patients were asked to complete the questionnaire about their opinions about responsibility for managing diabetes, setting targets and willingness taking medication in the waiting room and to return it anonymously in a prepaid envelope. It was stressed that it was of utmost importance that their opinion should be heard on these topics.

2.1. Measures

Our measures were based on qualitative research, that demonstrated variables such as age, weight, metabolic control, medication and distress to be of importance in understanding the patients' role in disease management [4]. The questionnaire started with a short introduction about the background and effectiveness of strict treatment targets. We assessed three different multinomial outcomes: (i) opinion about taking responsibility for managing your diabetes as much as possible: (very much) agree; (very much) do not agree, do not care; (ii) opinion about preferred person to determine your personal treatment targets (HbA1c; blood pressure; total cholesterol): myself, my physician or nurse, in cooperation with my physician or nurse, do not care; (iii) opinion about willingness to take medication to attain treatment targets: until all three targets are attained, one or two of the targets are attained, complaints or side effects arise.

We also assessed possible determinants of the above-mentioned opinions such as age, gender, educational level, ethnicity, setting of diabetes treatment [13], duration of diabetes, diabetes medication, the presence of macro- or microvascular complications and health related quality of life. The latter consists of mobility problems (i.e. problems with walking), self-care problems, pain and anxiety/depression measured by the (also in Dutch) validated EuroQol, general well-being measured by EuroQol-VAS (score range 0–100, where 100 represents best imaginable health status) [14] and three subscales from the (also in Dutch) validated Diabetes Health Profile (DHP-1 score range 0–100, where 100 represents no dysfunction), namely barriers to activity (i.e. impact of having diabetes and demands of treatment on activities of daily living and social functioning), psychological distress and disinhibited eating [15]. Disinhibited eating, or eating disinhibition, refers to the temporary loss of control of eating behaviour because of emotional arousal such as eating when not hungry, overeating and binge eating. [16]. Finally, we measured participants' opinions on perceived glycaemic control, weight and physical exercise, using 5-point Likert scales (range from very poor to very good). The questionnaire was pre-tested and piloted in 10 people with T2DM. Face validity was assessed by two physicians, a psychologist and a nurse.

2.2. Analysis

Data were analysed using SPSS for Windows (version 12.0.1, SPSS Inc., Chicago, IL, USA). Self-reported categorical outcomes were analysed as percentages.

For the outcome variables we performed three separate multinomial multivariable logistic regression analyses with three dependent variables including one reference. The reference categories were 'do not care' for (i) opinion about taking responsibility for managing your diabetes and for (ii) opinion about preferred person to determine your personal treatment targets and 'until complaints or side effects arise' for (iii) opinion about willingness to take medication to attain treatment targets. By using a backward stepwise method we identified which of the following determinants were independently associated with the

categorical outcome variables ($p < 0.05$). These were expressed in odds ratios (OR) and their corresponding 95% confidence intervals (95% CI). Possible determinants were analysed as proportions except for age that was analysed as a continuous variable. For use in daily practice, all determinants, except diabetes medication (none; oral glucose lowering agents (OGLA); insulin with or without OGLA use), were dichotomised including ethnicity (Caucasian yes/no), educational level (completed only primary school or less [low] vs. others [high]) setting of diabetes treatment (primary vs. secondary care), duration of diabetes (<5 years; ≥ 5 years), presence of macro- or microvascular complications (yes/no) and also participants' perceived diabetes metabolic control (average/(very) poor vs. (very) good), weight ((much) too low/good vs. (much) too high), physical exercise ((just) enough/(more than) enough vs. (much) too little) and mobility problems, self-care problems, pain/discomfort and anxiety/depression (all: none vs. some/serious). We dichotomised according to the median, results of the EuroQol-VAS (poor vs. good) and the three subscales from the DHP: barriers to activity, psychological distress and eating disinhibition (all: yes/no). Interquartile ranges (25–75%) were given for extra information. We tested for collinearity by analysing each determinant as an outcome in a regression model; all other determinants were used as independent variables. The setting of diabetes treatment (primary vs. secondary care) was entered in the model as a separate determinant of the outcomes.

3. RESULTS

Of 1029 consecutive persons with T2DM who participated, the data of 994 could be analysed. Of these 792 (80%) were mainly treated in primary and the remainder being treated in secondary care. In all, 35 persons could not be included in the analysis since their data were incomplete except for age (mean age 58.2 years; SD 9,8) and gender (51% males). The number of questionnaires returned per practice varied between six and 13. We have no data of the non-responders. The included participants had a mean age of 65 years (SD 10.3), 54% were males, 97% were of a Western ethnicity and 21% had completed only primary school or less (Table 1). Compared to T2DM patients treated in secondary care, patients in primary care were older, had a shorter duration of diabetes, used insulin less frequently and had fewer complications.

[TABLE 1.]

3.1. Opinions

Of all respondents, 62% (very much) agreed to take responsibility for their diabetes (Table 2), 48% preferred the setting of personal targets for HbA1c%, blood pressure and total cholesterol to be in cooperation with their physician or nurse. These were 68% and 51% respectively among participants treated in secondary care. Of all respondents 45% were willing to take necessary medication to attain all three targets. This was 48% among participants treated in primary care

[TABLE 2.]

3.2. Determinants of the patients' opinions

We did not enter ethnicity as a determinant in the multinomial analysis as fewer than 3% of the participants were of non-Western ethnicity. We did not find any collinearity between the possible determinants.

3.2.1. Opinion about taking responsibility for your diabetes

Among patients who expressed any opinion (agree or not agree) about taking responsibility for their diabetes compared with those who do not care, age, gender, educational level, setting of diabetes treatment, mobility problems, barriers to activity, eating disinhibition and glycaemic control all independently influenced patients' opinions (Table 3). Patients who did not agree to take responsibility perceived dysfunction by barriers to activity (OR 3.68; 95% CI 1.65–8.19), eating disinhibition (OR 2.41; 1.18–4.95), poor glycaemic control (OR 2.39; 1.16–4.91) and mobility problems (OR 2.28; 1.14–4.54). Among those who agreed to take responsibility were less people with a low educational level (OR 0.57; 0.37–0.88), less males (OR 0.59; 0.42–0.84) and less patients treated in primary care setting (OR 0.59; 0.37–0.94).

[TABLE 3].

3.2.2. Opinion about preferred person to determine personal treatment targets

As only less than 2% of the participants preferred themselves as the person to determine treatment targets, we did not use this outcome in further analysis.

Among patients who expressed an opinion about the preferred person to determine personal treatment targets compared to those who do not care, none of the possible determinants independently influenced patients' opinion, except that patients with complications preferred to determine treatment targets in cooperation with their physician or nurse (OR 1.98; 1.03–3.80) (not in table).

3.2.3. Opinion about willingness to take medication to attain targets

Among patients who expressed an opinion about willingness to take medication to attain treatment targets compared to those who are willing to take medication only until complaints or side effects arise, gender, self-reported mobility problems, pain/discomfort and perceived barriers to activity independently influenced patients' opinions. Males were more willing to take tablets until all three targets are attained (OR 1.62; 1.17–2.25), as opposed to those who showed dysfunction by barriers to activity (OR 0.70; 0.50–0.98), perceived some/serious pain (OR 0.73; 0.54–0.98) and with mobility problems (OR 0.46; 0.24–0.88), who were less willing to do so (Table 4).

[TABLE 4.]

4. DISCUSSION AND CONCLUSION

4.1. Discussion

Although almost two-thirds of the patients with T2DM agreed to take responsibility for their own diabetes, in the opinion of nine out of 10 people the setting of targets should be done by or in cooperation with their physician or nurse.

Persons with T2DM who are also suffering from mobility problems, barriers to activity, eating disinhibition and poor glycaemic control are less willing to take responsibility for their diabetes. However, females, those with higher education and those treated for their diabetes in primary care setting are more willing to do so. Patients suffering from complications have a preference to determine treatment targets in cooperation with their physician or nurse. Males are more willing to take tablets until all three treatment targets are attained, but persons with perceived some/serious pain/discomfort or dysfunction by barriers to activity are less willing. Age is not a determinant of any of these preferences.

4.1.1. Taking responsibility

This study shows that most people with T2DM agree to take responsibility for their illness. Indeed, this underpins the emphasis that diabetes care professionals put on patients' own responsibility for the management of diabetes [7]. The present study shows that even before the stage of discussing self-management and setting treatment goals, doctors and nurses should ask for patients' opinions on responsibility and willingness taking medication, especially in case of complications or co-morbidity.

4.1.2. Who should determine personal treatment targets

The majority of the patients in this study wanted to take responsibility for their illness, but most of them did not want to set treatment targets for blood glucose, blood pressure and blood lipids. Indeed, usually patients are asked to take responsibility only for their blood glucose levels [17] and not for the other two targets. Although there is evidence that persons with defined treatment targets have more effective self-care behaviour [18], it was shown recently that less than two-thirds of patients with diabetes and also hypertension had knowledge about their personal blood pressure targets [19]. Besides, qualitative research shows that there is often disagreement between patients and providers on goals and strategies of diabetes management [20]. Others showed that improved patient-provider collaboration leads to improved treatment outcomes since greater agreement on treatment goals and strategies is likely [21]. The latter corresponds

with the finding in the present study that setting of treatment targets in cooperation with health care providers is preferred by patients with complications.

4.1.3. Willingness to take medication to attain targets

Although four out of 10 patients in this study were willing to take tablets until all three targets were attained, it may be difficult for patients to comply for long-time with a regimen of polypharmacy, especially since targets tend to become more strict [22]. However, as also four out of ten would stop medication when complaints might arise, it seems likely that low adherence to medication use might occur more frequently than health care providers suspect. This has also been reported by others [23]. The shift toward patient centeredness in the management of chronic diseases such as diabetes has led to an increased focus on shared decision making between patients and health care providers. However, misunderstandings about participation in prescribing decision between patients and health care providers are common and based on inaccurate assumptions by both [24]. The present study of patients' opinions about taking medication up to target, provides important information for health care providers to reduce such misunderstandings. Males were more likely to take tablets until all three targets had been attained. This gender difference, to our knowledge, has not been described before in patients with diabetes, but related differences in gender have been described elsewhere showing men to be more decisive than women in expressing the desire to know information on impact of medication [25]. Although age was not a determinant for any of the opinions we measured, others showed that older persons with diabetes type 2 usually comply initially with medication advice but will often show non-adherence after some time [26].

This is a robust study on the view of patients in both primary and secondary care in the Netherlands. It assesses the independent associations between a broad range of patients' characteristics and opinions with patients' preferences and perceptions about diabetes treatment. The study has some limitations. Firstly, we presented data on consecutive patients and could not control for possible selection bias. To our knowledge all consecutive patients were approached. There were no eligibility requirements. However, this is a study in both primary and secondary care and mean age, gender and educational level are representative for the Dutch population of people with type 2 diabetes [27] and [28]. But, the results cannot be generalised to non-Caucasians. Secondly, this study did not take into account clustering within practices or outpatient clinics, but since the number of questionnaires returned per practice or clinic were thirteen or less the effect of clustering may not be relevant. Finally, we did not assess health literacy; this might have been an important determinant, especially in elderly people [5]. Besides health literacy could be an explanation for the number of 35 persons that did not complete the questionnaire.

4.2. Conclusion

Recommended care for diabetes has shifted over the past decade to an approach that is more patient centered. Although the traditional 'sick-role' has been replaced by a wish for a more concordant approach, in which patients are encouraged to be independent and proactive, this study showed that leaving this role is not so simple for patients. Taking into account the characteristics of those who do not want taking responsibility or taking tablets until all three targets are attained, may be of help to provide more individualized care.

4.3. Practice implications

When the diagnosis diabetes has been established, doctors and nurses should ask for patients' opinions on self-management in order to tailor responsibility and treatment goals. They may use the following topics: what is the patient's opinion about taking responsibility for his/her diabetes as much as possible; who should be the preferred person to determine personal treatment targets and how willing is the patient to take medication to attain these targets.

CONFLICT OF INTEREST

No conflict of interest.

FUNDING

This study was made possible through a grant of the Dutch Diabetes Research Foundation (grant 2005.13.021).

DISCLOSURE

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

ACKNOWLEDGEMENTS

We thank patients and their primary care providers who participated in this study. Furthermore we acknowledge Ms Rebecca Stellato and Mr Peter Zuithoff for their statistical support.

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TABLES

Table 1 Baseline characteristics, health related quality of life and opinions of the total study population (n=994), subdivided in setting of type 2 DM treatment: primary (n=792) and secondary care (n=202).

	N		Total (%)	Primary (% of n=792)	Secondary (% of n=202)
Age	994	Mean (SD)	65.1 (10.3)	65.7 (10.4)	62.8 (9.5)
		≤64	47.8	22.4	20.1
		65-74	32.1	57.7	66.4
		≥75	20.1	19.9	13.5
Gender	994	Male	53.7	53.5	54.5
		Female	46.3	46.5	45.5
Ethnicity	971	Western	97.1	97.0	97.5
		Non-Western	2.9	3.0	2.5
Education level	987	Low	20.6	20.1	22.4
		Medium	64.6	66.4	57.7
		High	14.8	13.5	19.9
Duration diabetes	959	<5 years	43.5	50.2	17.7
		5-10 years	28.2	28.0	28.8
		>10 years	28.4	21.8	53.5
Medication diabetes	971	None	9.8	12.2	0.5
		Oral glucose lowering agents (OGLA)	59.5	71.2	14.1
		Insulin with or without OGLA	30.7	16.7	85.4
Complications T2DM	956	No	62.7	66.2	48.7
		Yes	37.3	33.8	51.3
EuroQol VAS (0-100) Perceived health status	913	Mean (SD)	74.0 (15.8)	69.82 (17.21)	69.82 (17.21)
		Interquartile range	65-85	67-85	60-80
		Poor-average (0-75) ^a	53.5	50.9	63.4
		Good (76-100) ^a	46.5	49.1	36.6
Mobility problems	991	None	62.3	64.9	51.7
		Some/serious	37.7	35.1	48.3
Self-care problems	991	None	95.9	96.5	93.5
		Some/serious	4.1	3.5	6.5
Pain/discomfort	986	None	51.3	53.3	43.5
		Some/serious	48.7	46.7	56.5
Anxiety/depression	989	None	79.7	80.5	76.5
		Some/serious	20.3	19.5	23.5
DHP Barriers to activity (0-100)	929	Mean (SD)	85.9 (13.2)	87.7 (11.7)	79.4 (16.8)
		Interquartile range	80.6-94.4	83.3-97.2	69.4-91.7
		No dysfunction (89-100) ^a	48.5	53.1	31.3
		Dysfunction (0-88.9) ^a	51.5	46.9	68.7
DHP Eating disinhibition (0-100)	968	Mean (SD)	70.1 (19.6)	70.3 (19.6)	69.5 (19.8)
		Interquartile range	60-86.7	60-86.7	60-86.7
		No dysfunction (66.8-100) ^a	55.6	56.8	51.0
		Dysfunction (0-66.7) ^a	44.4	43.2	49.0
DHP Distress (0-100)	905	Mean (SD)	88.9 (8.1)	89.6 (7.4)	86.3 (10.0)
		Interquartile Range	85.7-95.2	85.7-95.2	81-92.9
		No dysfunction (90.6-100) ^a	45.0	47.6	35.1
		Dysfunction (0-90.5) ^a	55.0	52.4	64.9
Opinion glycaemic control	962	(very) Good	81.4	84.7	68.8
		Average/(very) poor	18.6	15.3	31.2
Opinion weight	987	(much) Too low/good	38.6	41.0	29.2
		(much) Too high	61.4	59.0	70.8
Opinion physical exercise	988	(much) Too little	31.5	29.6	38.6
		Just enough/(more than) enough	68.5	70.4	61.4

Numbers given in percentages, unless otherwise indicated.

^a Dichotomised according to the median.

Table 2
Opinions of patients about taking responsibility and treatment targets ($n = 994$), subdivided in setting of type 2 DM treatment: primary ($n = 792$) and secondary care ($n = 202$).

Topic	N	Answering categories	Total (%)	Primary (% of $n = 792$)	Secondary (% of $n = 202$)
Opinion about taking own responsibility for (managing) diabetes	953	I agree very much	11.0	9.9	15.2
		I agree	50.6	49.9	53.3
		I do not care	29.9	32.1	21.3
		I do not agree	7.9	7.4	9.6
		I very much do not agree	0.6	0.7	0.5
Opinion preferred person to determine personal treatment targets	961	I do it myself	1.9	1.7	2.6
		My physician or nurse	41.0	42.0	37.1
		In cooperation with my physician or nurse	48.0	47.2	51.0
		I do not care (for treatment targets)	9.1	9.1	9.3
Opinion about willingness to take medication to attain treatment targets	925	Until all 3 treatment targets are attained	44.5	47.5	43.8
		Until 2 of the treatment targets are attained	8.4	11.2	7.8
		Until 1 of the treatment targets is attained	2.8	1.1	3.2
		Until complaints or side effects arise	44.2	40.2	45.2

Table 3
Determinants of patients' opinion about taking responsibility for their diabetes by multinomial logistic analysis. Odds ratios with 95% confidence interval (OR; 95% CI).

Outcome	Patients' opinion about taking responsibility ^a ($n = 708$)			
	I do not agree		I agree	
	$n = 53$ (7.5%)	Adjusted ^b OR (95% CI)	$n = 443$ (62.6%)	Adjusted ^b OR (95% CI)
Age	53 (7.5%)	0.95 (0.92–0.98)	443 (62.6%)	0.98 (0.96–0.996)
Gender				
Male	27 (6.7%)	0.81 (0.42–1.56)	237 (59.0%)	0.59 (0.42–0.84)
Education level				
Low	17 (12.9%)	1.70 (0.80–3.59)	65 (49.2%)	0.57 (0.37–0.88)
Setting of diabetes treatment				
Primary care	40 (7.3%)	0.84 (0.37–1.92)	333 (60.4%)	0.59 (0.37–0.94)
Duration diabetes				
≥ 5 years	25 (6.2%)	0.96 (0.93–0.99)	252 (62.7%)	0.89 (0.62–1.28)
Mobility problems				
Some/serious	30 (11.9%)	2.28 (1.14–4.54)	146 (57.7%)	0.95 (0.66–1.39)
Barriers to activity				
Dysfunction	43 (12.2%)	3.68 (1.65–8.19)	217 (61.6%)	1.20 (0.84–1.74)
Disinhibited eating				
Dysfunction	39 (12.3%)	2.41 (1.18–4.95)	189 (59.6%)	0.89 (0.62–1.27)
Opinion metabolic control DM2				
Average/(very) poor	21 (17.2%)	2.39 (1.16–4.91)	68 (55.7%)	0.87 (0.54–1.41)

^a The reference category is: *I do not care*.

^b Also adjusted for medication diabetes, complications, perceived health status, self-care problems, pain/discomfort, anxiety/depression, distress, opinion weight, and opinion physical exercise.

Table 4
Determinants of willingness to take tablets to attain treatment targets by multinomial logistic analysis. Odds ratios with 95% Confidence Interval (OR; 95% CI).

Outcome	Willingness to take tablets ^a (n = 699)			
	Until all 3 treatment targets are attained		Until 1 or 2 of 3 treatment targets are attained	
	n = 333 (47.6%)	Adjusted ^b OR (95% CI)	n = 70 (10.0%)	Adjusted ^b OR (95% CI)
Age	333 (47.6%)	0.99 (0.98–1.01)	70 (10.0%)	1.00 (0.98–1.02)
Gender				
Male	212 (52.9%)	1.62 (1.17–2.25)	40 (10.0%)	1.30 (0.76–2.23)
Education level				
Low	53 (43.1%)	0.96 (0.62–1.48)	14 (11.4%)	1.08 (0.55–2.14)
Setting of diabetes treatment				
Primary care	261 (47.5%)	0.83 (0.55–1.24)	52 (9.5%)	0.67 (0.36–1.27)
Mobility problems				
Some/serious	103 (41.4%)	0.76 (0.51–1.13)	23 (9.2%)	0.46 (0.24–0.88)
Pain/discomfort				
Some/serious	140 (42.0%)	0.73 (0.54–0.98)	42 (12.6%)	1.07 (0.67–1.71)
Barriers to activity				
Dysfunction	145 (42.3%)	0.70 (0.50–0.98)	38 (11.1%)	0.95 (0.55–1.64)

^a The reference category is: Only when no complaints or side effects.

^b Adjusted for duration diabetes, medication diabetes, complications, perceived health status, self-care problems, anxiety/depression, eating disinhibition, distress, opinion glycaemic control, opinion weight, and opinion physical exercise.