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One-year follow-up effects of diabetes rehabilitation for patients with prolonged self-management difficulties

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Abstract

The aim of this study is to determine effects and the role of facilitators of empowerment of a Multidisciplinary Intensive Education Programme (MIEP) for diabetic patients with prolonged self-management difficulties. Glycemic control (HbA1c), health-related quality of life (HR-QoL) and facilitators of empowerment (health locus of control and coping) were measured in 99 participants of MIEP at baseline (T0), 3 (T1) and 12 months (T2) follow-up and in 231 non-referred consecutive outpatients. HbA1c improved at T2, although initial improvement was partially lost. Patients improved in most HR-QoL domains, without any relapse at T2. At T2, participants no longer differed from the average outpatients in any outcome. Initially, the HbA1c of men and women improved equally, but at T2 women consolidated improvement, whereas men relapsed. After MIEP, patients became more empowered (both at T1 and T2), explaining additional variance in HR-QoL improvement. The aim of MIEP to empower patients, rather than trying to solve problems for them seems effective.

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Keywords: Diabetes mellitus; Patient empowerment; Patient education; Self-management

1. Introduction

A considerable number of diabetic patients do not gain sufficient benefit from regular care and experience difficulties in maintaining adequate self-management, as manifested in poor glycaemic control [1,2], measured by glycated haemoglobin (HbA1c) and psychosocial problems [1–5]. Additional intensive education, self-management and psychological interventions can support these patients in optimising glycaemic control and health-related quality of life (HR-QoL), both equally important outcomes of diabetes care [6,7].

Several characteristics of intensive diabetes self-management interventions contribute to their effectiveness. These relatively time-consuming and expensive interventions should be reserved for patients at particular high risk and for whom intensive standard care is insufficient [8]. Traditional diabetes education tends to focus primarily on improvement of knowledge in order to improve self-management, but knowledge alone does not result in improved glycaemic control, nor does it produce behaviour change [9–12]. Interventions are often effective in the short run but consolidation of effects is much more limited [9]. To achieve long-term self-management effects, changes in patients’ attitudes and motivation are more important than purely improving knowledge [13]. Effective education programmes must be individualised to a person’s lifestyle, must respect individual habits, incorporate social support and must be reinforced over time [14]. Treatment that incorporates metabolic and psychosocial factors is most effective, requiring close collaboration between diabetologists, diabetes nurse specialists, psychologists and other team members [15]. Not only the immediate effects of the intervention should be considered but also consolidation of these effects [9].
We developed a diabetes rehabilitation programme (Multidisciplinary Intensive Education Programme (MIEP) [16] for patients with prolonged self-management difficulties; e.g. poor glycaemic control and/or frequent or severe hypoglycaemia and/or diabetes-related psychosocial problems that could be unsatisfactorily treated in regular diabetes care. MIEP aims to empower patients to manage their diabetes in order to achieve more lasting effects in glycaemic control and HR-QoL. The translation from the education setting to real life situations is a key element in supporting patients integrating diabetes self-management into their lives. Since prolonged self-management difficulties are often clustered and do not usually only involve knowledge and skills deficits, MIEP focuses also on other education targets [17], including goal setting, problem solving and psychosocial counselling. By combining potentially effective elements of education and a strong collaboration between team members, MIEP attempts to help patients with a history of complex self-management problems that could not be treated adequately in regular care despite intensive concern.

The first aim of this study is to determine effects of MIEP in glycaemic control, HR-QoL and in facilitators of empowerment (i.e. coping and attribution of control over diabetes), immediately after the intervention and at 1-year follow-up. The second aim is to determine whether intended increases in empowerment are related to positive HbA1c and HR-QoL outcomes, directly after MIEP and at 1-year follow-up.

2. Methods and statistics

2.1. Rehabilitation programme

The Multidisciplinary Intensive Education Programme (MIEP) is conducted in the Centre for Rehabilitation of Groningen University Hospital, the Netherlands. Patients with prolonged self-management difficulties or diabetes-related psychosocial problems are referred from outpatient clinics in the region. MIEP is based on the empowerment approach [18,19] and aims to empower patients to set and attain their own treatment goals. MIEP can be considered a rehabilitation programme since it aims to help patients to achieve optimal functioning given the restrictions imposed by having diabetes. Moreover, MIEP uses an interdisciplinary approach, which is one of the features of rehabilitation. Some elements of traditional diabetes education are integrated in MIEP as well, because empowerment and traditional transfer of knowledge are complementary [20].

MIEP comprises of ten whole days of group sessions (fixed groups of 6–9 patients) and some individual support over 10 weeks. Follow-up visits take place at 6 and 12 weeks ($T_1$) and 1 year ($T_2$). The diabetes education team consists of a diabetes nurse specialist, diabetologist, dietician, social worker, psychologist, physiotherapist, occupational therapist and an activity therapist, who work together intensively. MIEP highlights a range of diabetes-related topics and has modules on self-management, diet, exercise, daily activities and employment, the psychosocial aspects of diabetes and behavioural coping strategies. Examples of psychosocial aspects discussed in MIEP are accepting to have diabetes, coping with stress, assertiveness, social relations (both work-related and private) and communication to others about diabetes. The programme uses a four-phase learning sequence. First a topic is introduced, followed by group discussion or practice. In the third phase, patients plan how to fit in a particular aspect into their daily lives, which is subsequently evaluated in the fourth phase. Using this sequence, offers patients the possibility to gain insight into many aspects influencing their diabetes, as well as to experiment to change their habit and make informed choices in their diabetes self-management. The contents are thus made relevant to the patients’ own experiences and goals and patients have the opportunity to practice, which is an important element of rehabilitation. Practice of new skills and feedback is especially important for improvements in coping behaviour. Education directed solely at patients’ own priorities do carry a risk of missing essential aspects of diabetes self-management [21]. However, by providing an educational framework, the coverage of all essential aspects is ensured. The programme has been described in more detail in a previous issue of Patient Education and Counseling [16].

2.2. Participants

In 1999 and 2000, 161 patients enrolled in MIEP, of whom 154 (96%) participated in the study and completed the baseline assessment ($T_0$). Patients <18 or >75 years old, patients with severe co-morbidity (physically and mentally) or poor command of the Dutch language were excluded. The first measurement was obtained when the patients had their admission interviews and time was scheduled to complete the questionnaire. Follow-up questionnaires were mailed to the patients’ home addresses to be obtained at the 3-months ($T_1$) and 1-year ($T_2$) follow-up visits. If necessary, patient received a reminder. Additionally, we obtained 2 HbA1c measurements in the year previous to MIEP from patients whose values had regularly been determined in the same laboratory. This was the case for 47 participants.

To obtain reference values, we selected 330 consecutive non-referred outpatients from the diabetes clinic of Groningen University Hospital, using the same exclusion criteria as MIEP. Two-hundred-and-thirty-one patients (70.0%) took part in the study after informed consent, completed one questionnaire and gave permission for using their most recent HbA1c measurement and that of approximately 4 and 8 months ago.

2.3. Measures

Glycaemic control was measured by means of HbA1c, a standard measure in diabetes for the percentage of glycated
haemoglobin, indicating glycaemic control in the previous 6–8 weeks. An HbA1c of $\geq 8.0\%$ was considered poor glycaemic control [6]. The number of hypoglycaemia encountered over the previous 4 weeks and the number of severe hypoglycaemia for which assistance was required were obtained by self-ratings.

Health-related quality of life (HR-QoL) was measured using the Rand-36 questionnaire [22,23]. Four of the original 9 subscales were applied to measure the core aspects of HR-QoL: physical functioning, social functioning, mental health and vitality. The subscales were transformed to 100-points scales with 0 representing the lowest and 100 the highest possible HR-QoL.

In diabetes research, several instruments have been used to indicate patients’ feelings of empowerment. In general, they include aspects of perceived control and coping with diabetes [18,20,24]. As measures of facilitators of empowerment, we used diabetes-specific questionnaires for health locus of control and coping. These questionnaires reflect MIEP’s focus on the patients’ own resources in handling their diabetes and the encouragement of an active approach to problems regarding self-management. Empowered patients should indicate more active and problem-directed coping, instead of avoidance and passive coping. Furthermore, an internal health orientation, which is also associated with better self-management outcomes, is considered to facilitate patient empowered [5,25,26].

Wallston [27,28] defined three health loci of control (HLOC): internal, chance and powerful others. HLOCinternal reflects the extent to which patients perceive their health (diabetes control) to be dependent on their own behaviour. HLOCchance is the extent to which patients perceive their diabetes control to be dependent on chance factors (i.e. fate or luck). HLOCpowerful others indicates whether patients perceive their diabetes control to be dependent on influential others, i.e. the physician. We used the Dutch diabetes-specific version of this scale [29]. This instrument has three subscales, each consisting of six items with 6-point agree–disagree Likert-scales. Scores were transformed to scores ranging from 0 to 100, where higher scores meant higher orientation on the subscale.

The revised Diabetes Coping Measure [30] was used. The revised DCM has 35-item subscales for tackling spirit coping, avoidance coping, and passive resignation, and a fourth subscale (6 items), derived from the ATT39, measuring avoidance coping, and passive resignation, and a fourth revised DCM has 35-item subscales for tackling spirit coping, instead of avoidance and passive coping. Furthermore, an internal health orientation, which is also associated with better self-management outcomes, is considered to facilitate patient empowered [5,25,26].

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The revised Diabetes Coping Measure [30] was used. The revised DCM has 35-item subscales for tackling spirit coping, avoidance coping, and passive resignation, and a fourth subscale (6 items), derived from the ATT39, measuring diabetes integration [31]. All subscales were scored from 0 to 100. High scores on Copingintegration and Copingtackling spirit indicate adaptive coping behaviour, whereas high scores on Copingavoidance and Copingpassive resignation indicate poorer coping.

### 2.4. Statistical analysis

SPSS 10.0 for Windows (SPSS, Chicago) was used for statistical analysis. To analyse patterns of change over time in glycaemic control, HR-QoL and determinants of empowerment general linear models (GLM) for repeated measures (ANOVA for repeated measures) were applied. Within-subject factors for HbA1c, the 4 subscales for HR-QoL, and the 7 indicators of empowerment (3 × HLOC, 4 × Coping) were defined in three separate analyses. Both linear and quadratic trends were calculated [32]. Linear trends test whether a straight line best fits the 3 assessments, meaning that patients improved throughout the entire study period. Quadratic trends test whether part of a parabola fits the assessments and determine if patients especially improved during the programme, and if effects levelled off in the follow-up period. For the 47 patients with two pre-MIEP HbA1c measures, a cubic (s-bended) trend was also determined, to test whether HbA1c improved only after participation in MIEP.

We compared the means of MIEP participants to the reference group of 231 outpatients at each measurement using independent samples t-tests. For the 178 outpatients with two HbA1c pre-measures and the poorly regulated (HbA1c ≥ 8.0%) outpatients, changes over time were determined using GLM.

Linear regression analyses were applied to determine whether intended improvements in empowerment were related to improvements in glycaemic control and HR-QoL. After controlling for the baseline value of the outcome, age and gender, we tested whether short-term changes ($T_1 - T_0$) in indicators of empowerment were predictive for short-term outcomes. Stepwise regression was used where predictors with highest significant additional predictive variance were subsequently entered in the model. Controlled-for variables were entered in a first step, using the enter method. For consolidation of effects we calculated changes in outcomes after MIEP ($T_2 - T_1$). After controlling for baseline measure, age and gender, the indicators of empowerment ($T_2 - T_1$) were then tested for.

### 3. Results

#### 3.1. Patients

Four patients discontinued MIEP for motivational reasons and of the 150 participants who completed the programme, 118 (79%) filled in a second questionnaire ($T_1$). One hundred and twenty-seven participants visited the 1-year follow-up session and had their HbA1c measured of whom 99 (78%) completed the third questionnaire ($T_2$). The decreases in the response rate at baseline (96%) and $T_1$ and $T_2$ is likely due to the assessment procedure described in 2.2, although patients who did not complete follow-up questionnaires did not state their reason for this. Patients who stopped MIEP between $T_0$ and $T_1$ ($N = 4$) or between $T_1$ and $T_2$ ($N = 23$) had significantly higher T0 HbA1c (8.94 versus 8.36, $P = .03$) and a lower $T_0$ Copingintegration (48 versus 60, $P = .04$). At $T_1$, no significant differences in any of the measures were found between the 23 patients who stopped
3.2. Effects of MIEP

3.2.1. Glycaemic control

HbA1c improved over time (linear effect: $P < .001$, Table 1). However, after $T_1$, the effect levelled off significantly (quadratic effect: $P < .001$), but at $T_2$, mean HbA1c remained significantly improved compared to baseline. Initially, participants’ HbA1c was significantly elevated compared to the reference group, but at $T_1$ and $T_2$ not longer differed. The mean HbA1c did not change in patients with an initial HbA1c of $<8.0\%$. The overall improvement was due to improvements in the initially poorly regulated patients with an HbA1c of $\geq 8.0\%$. No significant changes in hypoglycaemia were found. Although HbA1c improved 0.5% or more in 38% of the participants of MIEP between $T_0$ and $T_2$, 51% still had an HbA1c of $\geq 8.0\%$ compared to 65% at $T_0$ and 42% in the reference group. Nevertheless, any drop in high HbA1c decreases the risk for the development of diabetic complications [33,34] and a decrease of 0.5% HbA1c can be considered clinically relevant.

3.2.2. HbA1c before the intervention

Repeated measures analysis of the 47 patients with 2 additional measures in the year previous to MIEP indicated that HbA1c improved only from the time patients participated in MIEP. A cubic within-subjects contrast, although non-significant ($P = .06$), best fitted the four measurements indicating that HbA1c was stable until $T_0$ (8.46 before MIEP; 8.38 at $T_0$), then falling (8.06 at $T_1$), and then deteriorating somewhat after MIEP (8.26 at $T_2$). These 47 patients did not differ significantly in demographics, baseline HbA1c and HR-QoL from the other participants. Repeated measures analysis of the 178 patients of the reference group with 2 previous HbA1c measures indicated, as expected, no changes in the 8 months period (means ranged from 7.92 till 7.96). In the 76 outpatients with HbA1c $\geq 8.0\%$ at 8 months before data collection, mean HbA1c did not improve significantly ($P = .25$; means ranged from 8.91 till 8.75).

3.2.3. Health-related quality of life

Table 1 shows that participants of MIEP significantly improved in mental health and social functioning.
The quadratic contrasts indicate no drawbacks in HR-QoL in the 3–12 months post-MIEP, and especially in the case of social functioning, patients after MIEP clearly improved further. Differences between participants and references largely disappeared after MIEP.

3.2.4. Facilitators of empowerment

Patients became more empowered after MIEP (see Table 1). The linear within-subjects contrasts were significant for Copingavoidance, Copingpassive resignation and HLOCchance and HLOCpowerful others. Remarkably, patients further improved in Copingavoidance, and HLOCchance, HLOCpowerful others between T1 and T2. Only in Copingpassive resignation the quadratic contrast was significant, indicating that, in general, effects did not level off after 3-months follow-up. At baseline, participants of MIEP were less empowered in comparison with the reference group, but these differences largely disappeared after MIEP. Although Copingpassive resignation declined in participants, it was still significant higher than in the references at T2. On the other hand, participants had lower levels of Copingavoidance at 1-year.

3.3. Determinants of effects

The T1 outcomes were predominately predicted by their baseline values. Short-term changes in empowerment were little predictive for T1 outcomes. Patients with a greater reduction in HLOCchance indicated higher vitality and social functioning at T1 (β = −.26, P < .01 in both cases) after controlling for baseline values (see Table 2). This indicates that a decrease in HLOCchance is related to an increase in vitality and social functioning.

3.4. Determinants of maintenance of effects

Regression analyses revealed some interesting determinants for maintenance of effects. As shown in Table 3, gender and Copingavoidance predicted consolidation of HbA1c; female participants and patients who consolidated low levels of Copingavoidance were less likely to deteriorate 3–12 months post-MIEP. The mean HbA1c for women (N = 69) was 8.28 ± 1.13 at T0, 7.96 ± 1.10 at T1 and 7.90 ± 1.06 at T2. GLM in women showed that a linear within-subjects contrast best fitted these data (P = .001). For men (N = 60), mean HbA1c was 8.46 ± 1.11 at T0, 7.92 ± 1.18 at T1 and 8.21 ± 1.02 at T2. These data were best represented by a quadratic contrast (P < .001).

Patients who were better able to consolidate T1 levels of Copingintegration were more likely to maintain improvement or to further improve mental health and vitality after MIEP. To clarify these relations, changes in patients who further improved (N = 36) and who deteriorated (N = 34) between T1 and T2 in Copingintegration were compared on T2 – T1 mental health and vitality. Patients who did not change in Copingintegration (N = 20) were left out of this analysis. Patients improving in Copingintegration between T1 and T2, improved 6.2 ± 14.9 in mental health compared to a deterioration of 6.4 ± 16.2 in patients who deteriorated in Copingintegration. Patients who decreased levels of Copingintegration did not change on average in vitality (M = −1 ± 16.6), whereas patients who increased improved 8.018.5. Patients who were able to maintain low levels of Copingpassive resignation had better outcomes in social functioning at 1-year follow-up. The patients (N = 27) who decreased Copingpassive resignation between T1 and T2 improved M = 11.0 ± 23.2 in social functioning after MIEP and the patients who increased in Copingpassive resignation (N = 35) improved only M = 4.9 ± 17.7. Patients who consolidated a decrease in Copingpassive resignation and Copingpowerful others more likely consolidated or improved physical functioning 3–12 months post-MIEP. The mean improvement in physical functioning in patients who decreased in Copingpassive resignation was M = 9.2 ± 20.4, whereas patients who increased Copingpassive resignation decreased M = 2.2 ± 16.4 in physical functioning. The mean improvement in patients who decreased their levels of HLOCpowerful others between T1 and T2 (N = 38) was 6.4 ± 20.8, whereas patients who increased in HLOCpowerful others between T1 and T2 (N = 24) decreased M = 7.3 ± 13.3. To summarise, post-MIEP, maintenance of empowerment-best reflected by

<table>
<thead>
<tr>
<th>Δ(T2 – T1)</th>
<th>Predictors (T2 – T1)</th>
<th>ΔR²</th>
<th>β</th>
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<tr>
<td>HbA1c T0</td>
<td>HbA1c T0</td>
<td>.42</td>
<td>.65***</td>
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<tr>
<td>Mental health T0</td>
<td>Mental health T0</td>
<td>.45</td>
<td>.68***</td>
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<td>Vitality</td>
<td>Vitality T0</td>
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<td>HLOCchance</td>
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<td>Social functioning</td>
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<td>Physical functioning</td>
<td>Physical functioning T0</td>
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* P < .05.
** P < .01.
*** P < .001.
Coping\textsubscript{integration} and Coping\textsubscript{passive resignation} was associated with maintenance of effects in HR-QoL.

4. Discussion and conclusion

The results of this study show that the diabetes rehabilitation programme for diabetic patients with prolonged self-management difficulties has beneficial 1-year effects on glycaemic control and health-related quality of life. Moreover, patients on average used more adaptive coping styles and were less chance and powerful others oriented with respect to diabetes. Patients who maintained improved levels of the facilitators of empowerment consolidated effects in HR-QoL better. Women were better able to retain improved HbA1c after the intervention.

4.1. Discussion

Diabetes affects many aspects of life that are often strongly interrelated \cite{3,35,36}. MIEP is a multi-focus intervention where these interrelations were taken into account and aimed to help patients to better integrate diabetes into their lives. At baseline, marked differences between MIEP participants and references were found, illustrative for the specific target group of MIEP, whereas 1-year post-MIEP, participants barely differed from the group of average non-referred outpatients.

Some systematic reviews showed that initial improvements are vulnerable for relapse after the intervention ends \cite{13,37,38}, especially in medical outcomes \cite{38}. By focusing on patient-empowerment and the translation of education to the patients’ home settings, MIEP attempted to prevent relapse. Particularly, with respect to HR-QoL and facilitators of empowerment, MIEP succeeded in this and a small relapse in HbA1c was found.

In the present study, the increase in facilitators of empowered was particularly due to the reduction of maladaptive coping styles and loci of control. Apparently, MIEP particularly supports patients reducing inadequate patterns. The questionnaires used did possibly not measure all aspects of the broad paradigm of empowerment and probably are facilitators of empowerment rather than indicators of empowerment. Being a broad and relatively new paradigm \cite{39}, no consensus exists on how to measure empowerment in diabetes exactly. Several psychosocial outcomes could be considered in diabetes empowerment studies, of which the measures in our study are two options. Anderson et al. \cite{40} recently developed a diabetes empowerment scale that is actually a measure of psychosocial self-efficacy. The use of this questionnaire or another measure of diabetes related self-efficacy \cite{41} would have contributed to the measurement of empowerment. However, these newly developed instruments were not yet available when our study was conducted and they would not have revealed the reduction in inadequate patterns of dealing with diabetes found in the present study. Menon \cite{42} proposed a set of items measuring patients’ perceived control, perceived competence and goal internalisation to indicate empowerment, but no validated instrument has been developed based on these items so far.

For this study has a non-randomised design the results could be due to causes other than the intervention, e.g. regression to the mean. However, spontaneous improvement is not very likely in the MIEP-participants, because inclusion took into account that participants had a history of unsuccessful intensive regular care. These assumptions were supported by pre-MIEP HbA1c data.

Our second aim was to determine whether increases in empowerment were related to positive HbA1c and HR-QoL outcomes. Our results suggest that during the intervention period (short-term) patients improved fairly independently of changes in coping with diabetes. However, in order to maintain or further improve HR-QoL, is seems important to consolidate improvements in diabetes-related coping. An increase in HLOC\textsubscript{chance} during the intervention period was found to be related to better vitality and social functioning immediately after the intervention. Probably, patients who became particularly aware that outcomes in diabetes are not a matter of change and who less had the idea that diabetes is a condition with a bad prognosis which can not be influenced, reduced their feelings of ‘diabetes burn-out’ \cite{43}, resulting in better vitality and social functioning. For a further improvement in mental health and vitality, Coping\textsubscript{integration} was predictive and for a further improvement in social and physical functioning Coping\textsubscript{passive resignation} was predictive. To retain improvements in health-related quality of life, it seems important for patients to have made diabetes an integrative part of their life and to not passively withdraw from the self-management efforts diabetes requires.

Facilitators of empowerment were only found to be little predictive for effects in HbA1c but interestingly, women were better able to sustain improved HbA1c after MIEP. In general, men tend to engage more in unhealthy habits, e.g. Laasonen et al. \cite{44} but to our knowledge gender-related differences in HbA1c outcomes in diabetes interventions have not been published. A clear explanation for this could not be found in our data. Observing the mean HbA1c over time, mean HbA1c decreased 0.38% from baseline to 1-year follow-up in women and 0.25% in men, which is not a large difference. The gender effect was especially due to the different routes in which effects were achieved and not that evident in the overall effect. Moreover, men had significant higher HbA1c at both baseline ($M = 8.46$ in men, and $M = 8.28$ in women) and 1-year follow-up ($M = 8.21$ in men and $M = 7.90$ in women). The finding that men were able to particular improve HbA1c in the intensive intervention period ($T_0$ till $T_1$) but relapsed in the follow-up period, suggests that men in particular might benefit from additional ongoing contacts after the intervention focused on maintaining improved glycaemic control.
In conclusion, our results indicate that MIEP is a useful intervention for patients with prolonged self-management difficulties that could not adequately be treated in regular diabetes care. Using an empowerment approach and a focus on patients’ goals, patients improve their HR-QoL and indicate that they have more adaptive coping styles and loci of control at 1-year follow-up. Women in particular have good HbA1c outcomes at 1-year follow-up. Our results suggest that post-intervention coping styles are important in patients being able to maintain or even further improve HR-QoL and HbA1c outcomes.

4.2. Practice implications

Not all diabetic patients can be treated effectively in regular outpatient diabetes care. Diabetes rehabilitation offered by means of a Multidisciplinary Intensive Education Programme was effective in patients with prolonged self-management difficulties. Additional care, such as MIEP, should be considered for patients with poor glycaemic control or low health-related quality of life as it can help them to improve in these important treatment outcomes [7]. Moreover, the improvements in HbA1c reduce the risks for diabetic complications [33,34,45], even though many participants still could be classified as having poor glycaemic control. Determinants of empowerment should be considered in diabetes education, because improvements in knowledge alone do not result in long-term self-management changes. The aim of MIEP to empower patients to target their own diabetes goals, rather than trying to solve problems for them, seems effective.

References


