

Improving self-management of people with type 2 diabetes in the first years after diagnosis: Development and pilot of a theory-based interactive group intervention

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Abstract

Objectives: To describe how principles of self-regulation and social support could be integrated in a group intervention to improve self-management of people with type 2 diabetes mellitus in the early phase of illness and to pilot its suitability in a primary care setting.

Methods: Principles of the Common-Sense Model of Self-Regulation, Social Cognitive Theory of Self-Regulation and social support theories were integrated in the intervention. Based on this, a three-session group course was developed to challenge illness perceptions of participants that discourage adequate self-management, to practice goal-setting and behavioural actions and to create a supportive environment. The intervention was piloted with persons with early-stage (1–3 years post diagnosis) type 2 diabetes mellitus selected in general practice in the Netherlands. Data about the suitability of the intervention were retrieved by means of observation and audio-recording of the sessions, an evaluation form filled in by the participants and an evaluation meeting with the group leaders.

Results: In total, 16 type 2 diabetes mellitus patients participated in the pilot, who were divided into a group of single participants (N=8) and a group (N=8) who participated with their partner. Discrepancies between perceptions of one's own condition and type 2 diabetes mellitus in general were observed. Goal-setting and developing action plans appeared to be difficult tasks for many participants, whereas others felt these exercises were not useful as they did not feel a need to make changes in living with diabetes. The group-based format was appreciated as was the participation of partners.

Conclusion: Challenging the illness perceptions of persons with early-stage type 2 diabetes mellitus by a brief interactive group course is feasible and important, as many of these people tend to underestimate the seriousness of their diabetes. However, motivating persons with early-stage type 2 diabetes mellitus to participate in self-management interventions remains a challenge. Offering the intervention as an integral part of type 2 diabetes mellitus management in primary care is desirable.

Keywords

Self-management support, type 2 diabetes mellitus, illness perceptions, partner support

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Introduction

Over the past decades, many interventions have been developed to support people with type 2 diabetes mellitus (T2DM) in the important, yet challenging task of managing their condition. Reviews on the effectiveness of these self-management interventions have demonstrated positive but predominantly modest and short-term effects on behavioural and psychological outcomes.^{1–4} Effectiveness of self-management interventions may

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increase when the provided support is tailored to the specific needs and challenges that arise in the different phases of living with T2DM. The Dutch Diabetes Foundation therefore funded the Diacourse study, which aimed to develop and test three interventions to support self-management and improve the quality of life of people with T2DM belonging to three different target groups: (1) persons with a diabetes duration of 1–3 years, (2) persons with a diabetes duration of more than 3 years and (3) persons with T2DM who have recently been confronted with an acute coronary event (see Van Puffelen et al.,⁵ De Vries et al.,⁶ and Kasteleyn et al.⁷ for the study protocols). The Diacourse study was approved by the Medical Ethical Committee of the VU University Medical Center Amsterdam.

This article describes the development and pilot of the self-management intervention targeting the first group: people with T2DM who are in an early phase of living with diabetes. Our research questions are as follows:

1. Which theoretical principles of self-regulation and social support are relevant for improving self-management of persons with T2DM in the early phase of illness, and how can these principles be integrated in a group intervention?
2. How suitable is the developed intervention for persons with early-stage T2DM managed by general practitioners in primary care?

Relevant theoretical principles

The Common-Sense Model (CSM) of Self-Regulation^{8,9} posits that people have cognitive and emotional perceptions of a health threat, which act as a framework for their actions to respond to the threat. With regard to T2DM, its perceived seriousness and controllability are considered most influential to guide self-management: perceived control, either by one's own behaviour or by medical treatment, predicts a more or less healthy lifestyle, whereas the perceived seriousness and impact of the illness relate to people's emotional responses.^{10,11} Many people with T2DM do not experience diabetes-related symptoms or complications during the first years after diagnosis. This could lead to underestimation of the seriousness of T2DM and, consequently, of the necessity to engage in self-management directly from diagnosis.¹² As the intention to behavioural change starts with creating awareness of the need to take action,¹³ we chose illness perceptions as the central concept to intervene on in this target population of people with early-stage T2DM.

Other interventions to support self-management of T2DM – not specifically targeting persons in the early phase of illness – have focused on self-efficacy.¹⁴ Self-efficacy is a central concept of the Social Cognitive Theory (SCT) of Self-Regulation^{15,16} and has been proven an important determinant of T2DM self-management.^{14,17} Based on this theory, it could be expected that individuals with T2DM engage in self-management if they believe that (1) adequate self-management

will result in outcomes that are beneficial to them and (2) they are able to self-manage their condition successfully. In addition, goal-setting – and its link with self-efficacy – is believed to be an important source of motivation for behavioural change in the SCT. Having individuals setting realistic, manageable and proactive goals in a stepwise manner can increase motivation for health behaviours, in addition to individuals' perceived self-efficacy to achieve these required and/or desired changes. Therefore, we integrated goal-setting and action plan development in our intervention, in addition to exploring and challenging personal illness perceptions.

Finally, we integrated insights from social support theories^{18,19} in the intervention, as a person's close others could play an important role in overcoming barriers in maintaining a healthy lifestyle and provide support in coping with T2DM.^{20–22}

Description of the intervention

Considering that many people we aimed to reach with the intervention would not experience severe symptoms or activity limitations as a consequence of T2DM, and as we did not want to discourage these people or make them think they did not belong to the target population, we developed an intervention that was easily accessible, brief, interactive and course-like. This interactive group course consisted of three 2-h monthly sessions and a booster session 3 months after the last session. Group size was set at 5–10 persons with T2DM. Participants were encouraged to bring their partner (or a close friend or relative), but this was not required. The sessions were designed to be guided by two course leaders. Diabetes or practice nurses who participated in a 4-h training prior to the start of the intervention were eligible to lead the sessions. To guide the sessions, we developed a manual for the course leaders and a workbook for the participants, including assignments and practical and theoretical information about the topics discussed during the sessions. Box 1 provides an outline of the course sessions.

Description of the course sessions

Session 1 focuses on participants' (and partners') illness perceptions. The aim of the session is to create awareness of own personal beliefs of T2DM and how these influence coping with the illness in daily life. Participants are asked to share their perceptions of the seriousness of their (partners') diabetes, feelings of control, worries and concerns and perceived consequences of the illness on their lives. Maladaptive perceptions are challenged and adaptive perceptions strengthened through the provision of (medical) information and positive practical examples from other participants. The group discussion aims to focus on the seriousness of T2DM and its controllability by one's own actions and medical treatment. As a homework assignment, participants are asked to keep a record of the difficulties and challenges they encounter in living with

Box 1. Outline of the course sessions.

	Aim	Methodology
Session 1 Illness perceptions/ attitudes towards diabetes and self- management	<p>Creating awareness of differences in illness perceptions and their link with behaviours.</p> <p>Increasing positive outcome expectancies of diabetes self-management and treatment by confirming perceptions of seriousness and controllability.</p>	<p>Group discussion of participants' different perceptions on the seriousness, controllability and consequences of diabetes, mediated by the course leaders.</p> <p>Challenging maladaptive perceptions in the group through the provision of medical information about diabetes and its treatment.</p>
Session 2 Self-efficacy/ empowerment	<p>Increasing self-efficacy beliefs and empowerment through working on feasible and specific goals for behaviour change.</p>	<p>Group discussion of the homework assignment on diabetes-related challenges. Development of personal diabetes-related goals and action plans to overcome these challenges, guided by the course leaders.</p>
Session 3 Social support	<p>Creating awareness of (un)helpful ways of support and the possible gap between wanted and received support.</p> <p>Overcoming barriers in behaviour change by (asking) support from others.</p>	<p>Group discussion on achievements and challenges encountered in the pursuit of personal goals and action plans. Group discussion on partner support that is perceived helpful and whether received support is in line with or deviates from what is perceived helpful, mediated by the course leaders.</p> <p>Integrating help or support from others to overcome the experienced barriers in goal and action plan attainment, guided by the course leaders.</p>
Booster session	<p>Providing a reminder of the techniques learned during the course.</p>	<p>Group discussion on the experiences on achieving the personal goals/actions specified in the action plans and on the questions or challenges that have arisen during the past 3 months, mediated by the course leaders.</p>

diabetes during the following month. Participants are asked to indicate (1) which aspects or situations in living with diabetes they perceive to be challenging, (2) when these situations occur and (3) how they usually react to these situations as a preparation for the second session.

In session 2, goals and action plans are developed and discussed. The aim of the session is to support the participants in setting realistic, short-term goals and using stepwise plans to reach these goals. At the start of the session, the homework assignment on the encountered challenges is discussed and used as input to discuss the relationship between thoughts, feelings and behaviours. It is also used as a starting point for participants to set their own goals for the short term and develop action plans on how to achieve them. Participants are encouraged to set a goal that they consider personally important and feel capable of achieving within the timeframe of the course. Long-term goals are translated into short-term intermediate goals and action plans, using principles of implementation intentions: (1) What do you plan to do? (2) How much or how often do you plan to do this? and (3) When exactly will you do this? At the end of the session, the participants are instructed to implement their action plan for the next month.

Session 3 focuses on discussing ways to ask for support and (un)helpful supportive interactions. Special attention is given to providing and receiving helpful and desired support from one's close environment. At the start of the session,

participants are asked to share whether they had achieved the goals of their action plan (formulated in session 2) and the helping and hindering factors they experienced. Next, (un) helpful and (un)desired ways of providing and receiving social support are discussed: which types of support do people with T2DM receive and is this in line with what they want/need. Furthermore, the role of the partner in overcoming barriers to achieve future goals is explored. Finally, participants are asked to develop a new action plan for the next 3 months, including their partners' support to overcome potential barriers.

During the booster session, the course leaders and participants evaluate the course and discuss the (non)achievement of the goals set during the third course session. Questions and needs that have arisen during the 3 months since the third session are also being discussed.

Pilot of the intervention

To examine the suitability of the intervention for persons with early-stage T2DM (research question 2), we piloted three sessions guided by the following questions:

- 2.1. How many persons with early-stage T2DM registered in general practice are willing to participate in the intervention?

- 2.2. How are the format and content of each of the sessions evaluated by the participants and group leader(s)?
- 2.3. Do participants consider the intervention useful, irrespective of whether or not they experience diabetes complications?
- 2.4. How does the participation of partners (or close others) influence the sessions?

Methods

Setting and selection of participants. Potential participants were selected by a practice nurse from a general practice in the Netherlands. Inclusion criteria were (1) a diagnosis of T2DM and (2) an illness duration between 1 and 3 years after diagnosis of T2DM. Exclusion criteria were (1) unable to speak or understand the Dutch language, (2) cognitively unable to participate and (3) receiving treatment for severe psychological or psychiatric problems. Eligible persons received a written invitation to participate; those who decided to participate gave informed consent. Sociodemographic and illness-related characteristics from the selected patients were retrieved from the general practice's medical records.

Delivery of the intervention. Although the intervention was designed to be guided by trained nurses, we wanted a health psychologist to guide the sessions during the pilot, to ensure that psychological principles could be evaluated properly. During the first session, a practice nurse was also present to respond to questions about T2DM and its treatment. As the pilot would take too long when organising the sessions monthly, they were organised fortnightly. Given the purpose of the pilot and the questions we wanted to answer, we felt this approach was acceptable.

Data collection and analyses. To examine how many persons with early-stage T2DM are willing to participate in the intervention (2.1), we counted the number of invited persons who gave informed consent, and we tested for differences between the participants and non-participants in gender and age distribution, diabetes treatment and presence of diabetes complications.

To examine how the format and content of the sessions are evaluated by the participants and group leader(s) (2.2), whether the participants consider the intervention to be useful (2.3) and how the participation of partners, or close others, influences the sessions (2.4), data were collected by the following:

- Observation and audio-recording of the sessions. A researcher was present during all sessions and took notes. Each session was audio-recorded and each recording was listened to by two researchers.
- Debriefing of all sessions with the health psychologist guiding the sessions, and an oral review after the

intervention with the practice nurse involved in recruitment of the participants and the first session.

- An evaluation form filled in by participants with T2DM after the third session. The evaluation form addressed the following aspects of the intervention: appreciation of the format and content of the intervention, perceived usefulness of the intervention, intention to make changes related to T2DM self-management, overall grade and recommendation of the course to others.

The notes that were made by the researchers during the course sessions, after listening to the audio-recordings and debriefing with the health psychologist and the oral review with the practice nurse, were discussed within the core research team during biweekly meetings. Observations and experiences of the researchers involved were exchanged and discussed, in order to reach consensus on the interpretation of the qualitative data from various resources. Data collected by the written evaluation forms were analysed by descriptive quantitative analyses; additional written comments were added to the researchers' notes and discussed during the meetings of the core research team.

Results

Willingness to participate. Of the 74 eligible people with T2DM who received a written invitation, 16 agreed to participate (22%). Reported reasons for non-participation were not being interested ($n=25$), not being able to attend the sessions ($n=12$), not having a partner to attend the sessions with ($n=5$) and being satisfied with usual care provided by diabetes care professionals ($n=3$). Table 1 shows the demographic and diabetes-related characteristics of the participants with T2DM. No significant differences ($p < .05$) were found between participants and non-participants in age, gender, marital status, type of diabetes treatment and the presence of diabetes complications.

The 16 participants were divided into two groups: one group ($n=8$) participating with their partner and one group ($n=8$) attending the sessions alone. Participants in this latter group indicated that they did not have a partner or close other to bring with or reported that their partner was not willing or unable to attend the sessions.

Evaluation of the format and content of the sessions. Of the 16 participants, 13 with T2DM returned the evaluation form. Also, two partners filled in the form. Since these persons with T2DM and partners provided similar feedback, their data were combined for analysis ($N=15$).

Based on our observations, the group-based setting seemed to work well in terms of sharing experiences and discussion. Participants interacted constructively and showed much interest in how others experienced living with diabetes. In the group with persons with T2DM and partners – which was obviously twice the size of the other group

Table 1. Sociodemographic and diabetes-related characteristics of persons with T2DM participating in the pilot (N = 16).

Characteristic	n	%	Mean	SD
Age, in years			68.0	8.4
Gender: male	8	50		
Married or cohabiting	10	63		
Diabetes duration, in years			2.0	0.9
Diabetes treatment:				
Lifestyle advice only	7	44		
Oral hypoglycaemics	9	56		
Insulin	0	0		
Diabetes complications: present	2	13		

– participants had the tendency to start talking in smaller subgroups, which was considered disruptive at times and made it more difficult for the course leader to guide the discussion. The majority of the responding participants were happy with the frequency, duration and time of the sessions. Three respondents felt that the number of sessions was too high, while two others preferred more sessions.

The first session was rated as (very) useful by nine respondents; five rated this session as fairly useful and one as not useful. One person described that *hearing how others think about and deal with their diabetes* was very useful. Similar comments were made by others. A notable observation was that persons with T2DM attending this session perceived T2DM to be a serious disease, but considered their own condition as less serious. Moreover, although participants generally stated they considered T2DM to be a (very) controllable condition, several barriers and challenges in managing their diabetes were expressed.

The second session was rated as (very) useful by seven respondents; two rated this session as fairly useful, five as not useful and one did not answer the question. During this session, it was observed that setting relevant goals and developing realistic and specific action plans were rather difficult tasks. For instance, all participants set goals to improve their eating habits or exercising, while stating at the same time that there was not much room for improvement in these domains. Moreover, these goals were not in accordance with the difficulties they reported in managing their diabetes, which were predominantly in the psychological domain of coping with the illness. The accompanying action plans were often not specific enough (e.g. ‘My plan for next week is to be more physically active’). One-third of the respondents on the evaluation form rated action planning as not useful for them. Some explained their answer by stating that they did not experience difficulties in managing their diabetes and therefore did not need an action plan. Others felt that they were able to make the desired changes without the use of action plans.

Of the 15 respondents on the evaluation form, 8 rated the third session as (very) useful, 6 as fairly useful and 1 as not useful. According to participants’ verbal feedback after the session, this last session was appreciated by most participants

with T2DM as well as partners. The focus of this session was on being supported by one’s significant others in dealing with T2DM. One person attending the group without a partner or significant other commented that *after all, you are still the one who has to deal with the illness*. In the group of persons participating with their partner, none of the participants with T2DM reported insufficient or unhelpful partner support. However, it was noticed that one couple did not agree on the support provided by the partner, but decided not to share this with the group.

Overall evaluation of the intervention. Respondents evaluated the total course, on a scale from 1 to 10, on average with 7.4 (range: 6–10). Nine respondents indicated to probably or definitely apply the information and skills learned during the course in the near future. Seven participants reported that they had already made changes in their personal lives thanks to the course. In alignment with the intentions expressed, these changes were predominantly related to healthy eating, exercise and weight control.

Nine respondents would probably or definitely recommend the course to other people with T2DM, *because you always may learn something new*. One person, however, would recommend the course only to people with T2DM in a more advanced stage of the illness. Some persons who were not certain whether they would recommend the course to others expressed doubts about the usefulness of the course in the absence of experiencing problems in living with diabetes. The comment of another hesitating person that *the success of the course depends too much on the motivation of other participants* may point into the same direction.

Influence of partners on the sessions. We observed that all partners who attended the sessions worked together with their partner with T2DM on the assignments and actively participated in the plenary discussions. However, it also came to fore that the presence of partners may have its influence on the extent to which people with T2DM feel the ability to freely discuss (un)helpful ways of partner support.

Discussion

In this article, we described relevant theoretical principles of self-regulation and social support for developing self-management interventions for persons with early-stage T2DM and assessed the suitability of a group-based interactive course based on these principles.

Relevance of theoretical principles

Our decision to focus on illness perceptions as the central theoretical concept to activate people with early-stage T2DM for self-management appears to be supported by the experiences of participants and course leaders and our observations during the pilot. It was noticed that many participants with T2DM in

our pilot considered their own condition to be less serious than T2DM in general, which could be due to the fact that most did not experience any diabetes-related symptoms or complications yet. Challenging people's illness perceptions is therefore of utmost importance, since the patient activation starts with a firm belief in one's own role and need to take action.^{13,23} Without this belief, as shown during the pilot, people will not be motivated to set personal goals for behavioural change and make concrete action plans accordingly.

Self-efficacy is widely known to be an important determinant of diabetes self-management.^{14,17} However, whether a brief group intervention is suitable for all persons with T2DM to improve their self-efficacy of T2DM self-management is less clear. During the pilot and its evaluation, many participants indicated to have made some improvements in their lifestyle and self-care behaviours, which were in line with the action plans they had developed. Notwithstanding that, we also observed during the second and third sessions that setting relevant and concrete goals and developing corresponding action plans were rather difficult for many participants. Moreover, they indicated during the evaluation that they encountered many barriers in achieving their goals and plans. Based on these experiences, we believe that goal-setting and action planning only makes sense if patients are convinced that they need to alter certain aspects of their lifestyle or health behaviours and that these activities need to be exercised, stimulated and continuously monitored over time. Hence, introducing goal-setting and action planning to patients as part of a brief group intervention may be useful, if follow-up is ensured by integration in T2DM management.

Finally, the importance of partners in the daily self-management of T2DM (e.g. exercising together, cooking healthy meals, joining at appointments with health care providers) came to the fore during the group discussions. Also, partners were involved to provide support in the development and execution of the action plans of people with T2DM, for instance, in helping them overcome barriers by joining them on their planned walks or taking into account their diets during grocery shopping. Our experiences confirm the important role of partners in the management of diabetes, which mainly takes place in the context of family life, and also underline the importance of having partners participate in self-management support interventions.^{24–26} Even though we did not observe substantial differences in the perceptions of patients and their partners during the pilot, other studies have shown such differences, with partners generally perceiving T2DM as a more serious disease^{25,26} and showing a better understanding of the condition than people with diabetes themselves.²⁴ Considering this, we believe that involving partners in T2DM self-management interventions may be helpful to counteract underestimation of T2DM in patients.

Suitability of the intervention

Overall, the group-based interactive course we developed seemed to meet the needs of the participants. The group-based

format was appreciated by both course leaders and participants and supported the notion that group discussion can be a valuable element of self-management support.²⁷ Group discussion enables patients to collaboratively work on self-management in an environment in which they are surrounded by individuals facing similar tasks and challenges and where they can mirror themselves against others, share experiences and exchange helpful ways to integrate T2DM self-management within other goals and priorities. Previous studies have demonstrated that group support can have positive effects on health behaviours and psychosocial and clinical outcomes in patients with diabetes.^{27–30}

Inclusion of partners was appreciated by both persons with T2DM and partners. Discussing (un)helpful ways of support was generally perceived useful by the participants, also in the group attending without a partner or significant other. Hence, delivering the course was feasible and participation was considered valuable, irrespective of whether partners participated or not. Nevertheless, we believe that it is important to encourage persons with T2DM to participate in self-management interventions together with a partner or close other, considering the impact that social support can have on the daily management of diabetes.^{20–22}

The evaluation of the total course and the three sessions was generally positive and the vast majority of the participants who filled in the evaluation form stated they would recommend the course to other persons with T2DM. The main concern is the low participation rate: only 22% of the people with T2DM invited to participate in the course actually did. We had already limited the number of course sessions to three, as we expected people with T2DM who do not experience substantial symptoms or complications to be not interested in a more comprehensive intervention. Nevertheless, the low participation rate suggests that reaching people with early-stage T2DM remains a challenge. Indicated reasons for non-participation, such as the diabetes being 'still mild', not needing to take medication or experiencing complaints, point to underestimation of T2DM. To encourage persons with early-stage T2DM to participate in a self-management intervention, primary care physicians and nurses could discuss and agree with each patient how he/she will develop self-management knowledge, skills and behaviours as an integral part of the patient's individual care plan.

Limitations

Although the number of participants in the pilot was sufficient to evaluate the intervention process, it did not allow to draw firm conclusions regarding the influence of partners on the group process. As described earlier, delivering the course with and without partners worked well, and inclusion of partners was appreciated by both persons with T2DM and partners. However, whether and how partners influence the intervention process remains unknown.

Furthermore, we cannot reflect on the ability of the future course leaders (diabetes and practice nurses) to deliver the

course, since we had chosen to have a health psychologist guide the pilot sessions. It should be noted that the training of the future course leaders will be provided by the same health psychologist who guided the pilot sessions. In this way, experiences from the pilot will be directly integrated in this training.

Implications for intervention development

The lessons learned from the pilot call for some adaptations in the content and delivery of the intervention. Our experience with the second session suggests that people need to perceive some difficulties in the way they emotionally or behaviourally manage their diabetes, in order to benefit from training in goal-setting and action planning. Persons with T2DM who do not perceive any difficulties or challenges managing their diabetes might benefit more from paying extra attention to their illness perceptions, instead of asking them to set goals and develop action plans they consider unnecessary. Persons who do perceive difficulties or challenges in managing their illness are more likely to benefit from goal-setting and action planning exercises, as these people will feel a need to make changes. Assessing diabetes-related uncertainty, coping and its perceived impact during the recruitment phase by a short screener may help to identify the two groups and offer them a second session focusing either on challenging illness perceptions or on goal-setting and action planning.

Furthermore, we suggest to let participants work on the course assignments during the sessions in guided subgroups, instead of individually or alone with the partner. By working in guided subgroups, participants could inspire each other setting relevant and realistic goals and developing concrete action plans. Moreover, as discussing partner support in the presence of the partner could be delicate, this may be better discussed in guided subgroups for people with T2DM and partners separately. Finally, we expect that working in smaller subgroups on the assignments will decrease the chances of ‘disruptive’ talk during the sessions.

Conclusion

Challenging the illness perceptions of persons with early-stage T2DM by a brief interactive group intervention is feasible and important, as many of these people tend to underestimate the seriousness of their diabetes. However, motivating persons with early-stage T2DM to participate in self-management interventions remains a challenge. To encourage persons with early-stage T2DM to participate in a self-management intervention, primary care physicians and nurses could discuss and agree with each patient how he/she will develop self-management knowledge, skills and behaviours as an integral part of the patient’s individual care plan.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

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Informed consent

Written informed consent was obtained from all subjects before the study.

Trial registration

Netherlands National Trial Register (NTR): NTR3302.

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