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General discussion
GENERAL DISCUSSION

Type 2 diabetes (T2DM) confronts patients with the task of adapting to living with a chronic and progressive condition on a daily basis. The Diacourse study was developed to support patients in different phases of T2DM by examining the needs and challenges that (may) arise over the course of illness, and by developing and offering tailored self-management support. This thesis describes two parts of the Diacourse study in which we aimed to:

• Gain insight into the illness perceptions, self-management behaviours and quality of life of patients over the course of T2DM (part 1);
• Develop a group-based self-management support programme for recently diagnosed T2DM patients and their partners, and evaluate its effectiveness (part 2).

In this chapter, the results of the studies described in the previous chapters are summarised and discussed. Furthermore, a number of methodological aspects of the studies will be addressed, followed by a reflection on the implications of the findings for clinical practice and for further research.

Part 1: Illness perceptions, self-management and quality of life over the course of illness

The Diacourse study was based on the assumption that T2DM patients’ self-management tasks change over time, for example, as a result of changes in treatment or the development of complications. When we focus on the first years after diagnosis, T2DM appears to be managed differently in the presence of complications, which is described in chapter 2. Where T2DM is generally perceived as a rather mild and controllable condition in this phase, patients who already experience complications perceive their condition as more unpredictable and less controllable by own behaviours and treatment, with a more serious impact on their daily life and emotional state. Patients with complications are also found to be more physically active and to check their feet more often than patients without complications. Weak, but logical correlations are found between illness perceptions and self-care; beliefs of personal control and T2DM being a chronic condition positively relates to healthier exercise and dietary behaviours and increased foot care respectively, while perceptions of own behaviours as a cause for T2DM negatively relates to fruit and vegetable intake and not smoking. Differences in self-care over the course of illness have been described in chapter 3, where the combined data of all three studies show that patients with a longer diabetes duration are less physically active, but monitor their glucose levels more frequently than patients who were more recently diagnosed. Less physical activity appears to be primarily related to the presence of macrovascular complications, whereas the frequency of glucose monitoring relates to the type of treatment, in particular whether patients are on insulin treatment or not. Furthermore, it appeared that patients who experience microvascular complications are less
likely to eat healthy, but more likely to perform foot care. **Chapter 4** indicates that T2DM patients with a longer illness duration experience more diabetes-related distress. This can be primarily explained by their higher chance of experiencing microvascular complications and of being on insulin treatment. Nonetheless, overall levels of diabetes distress appear to be low throughout the course of illness.

The variation in patients’ illness perceptions, self-management and diabetes-related distress over the course of illness appears to relate to the presence of complications and the intensity of the treatment regimen (e.g., insulin) rather than diabetes duration itself. The findings among our recently diagnosed sample support previous studies indicating that T2DM patients generally underestimate the seriousness of their condition and overestimate their ability to control its course until complications arise[1–3]. The positive associations between perceived controllability and engagement in healthier lifestyles confirm that perceived personal control and treatment control are important determinants of self-management [4–7] or, in terms of Social Cognitive Theory (SCT), that self-efficacy beliefs and outcome expectancies are important determinants of health behaviour [8]. The negative association between physical activity and macrovascular complications is in accordance with the known increased risk of developing heart problems as a result of a lack of exercise [9,10], and – reversely - the fear and discomfort of patients who recently experienced an Acute Coronary Event (ACE) regarding physical activity [11,12]. Finally, our finding that microvascular complications and insulin treatment relate to higher levels of distress in T2DM patients is backed up by previous studies [13–16], although diabetes-related distress is shown to be more strongly associated with psychological factors, such as coping style and social support, than clinical factors [15,17].

Overall, our findings support the notion that complications could act as a cue to action by causing T2DM patients to take their condition more seriously and, consequently, creating a sense of urgency to engage in self-management to prevent further deterioration of their condition [1,3,18]. However, in order to improve diabetes self-management, patients need to understand that these complications relate to their diabetes. For example, the majority of participating patients in our study who had recently experienced an ACE did not attribute this event to their diabetes [19], which may explain the lack of association between the presence of macrovascular complications and increased levels of diabetes-related distress in our study. Likewise, self-management behaviours will most likely only be triggered when perceived as an effective strategy to reduce the risk of further progression or development of complications (i.e. positive outcome expectancies of these behaviours) [20]. Our finding that the presence of microvascular complications is positively associated with more frequent foot care - a diabetes-specific self-care behaviour - but not with more generic health behaviours such as exercising, healthy eating and non-smoking, seems to confirm this. Reversely, it should be noted that the presence of complications may also result in less self-management when these complications interfere with the performance of specific behaviours (e.g., foot problems may hamper physical activity) or cause patients to feel less able to successfully perform these
behaviours (i.e. negative self-efficacy beliefs) [20]. This seems to be reflected by the negative association between the presence of macrovascular complications and physical activity, and the lower levels of perceived personal control found among patients with complications.

**Part 2: Supporting self-management in the early phase of T2DM**

The Living with diabetes course aimed to support patients and their partners in living with T2DM during their first years of illness, both behaviourally and emotionally. The protocol of the RCT on the effectiveness of the intervention was described in chapter 5. The brief interactive group-based course that focused on establishing adaptive illness perception models, supporting (proactive) goal and action plan setting and activating helpful ways of partner support appeared to be a suitable and acceptable manner to target self-management in this patient population, as indicated by the pilot study in chapter 6, but probably only for those who experience some degree of diabetes-related uncertainty or challenges. Results on the effectiveness of the course, as examined in chapter 7, indicate that participation has a short-term positive effect on patients’ lifestyles, and a longer positive effect on their empowerment. Immediately after the course, the participants were more physically active and reported a higher intake of fruit and vegetables than the control group. These behavioural effects, however, did not sustain until six months after the course, despite the participants still feeling more empowered to manage their condition and its treatment. Levels of diabetes-related distress appear to be already low in this patient population, and remained unaffected by the intervention over time. Also, no significant intervention effects were found on patients’ illness perceptions and perceived partner support.

The short-term improvements in lifestyle behaviours and the longer-term increased empowerment following the Living with diabetes course are largely in accordance with previous findings of self-management support in general [21–24] and CSM-based diabetes support specifically [25–30]. CSM-based intervention studies in T2DM have shown promising effects on health behaviours and outcomes, for instance, on glycaemic control in poorly controlled patients [25] and on lifestyle behaviours, weight loss, depression and medication adherence in ongoing and newly diagnosed patients [26-30]. However, similar to our intervention, behavioural effects usually diminished or disappeared in the long run. Contrary to our expectations and the results of the other CSM-based interventions [25–27], we did not find any significant intervention effects on participants’ illness perceptions and attitudes.

Changing diet and increasing physical exercise are acknowledged to be among the most difficult aspects to tackle in diabetes management, particularly in the long-term [31–33]. Individuals are often required to change already (life)long existing behavioural patterns, as physical activity and diet are rather part of a person’s overall lifestyle than diabetes-specific behaviours. Additional challenges are posed by the fact that the effects of (un)healthy behaviours often take a long time to become visible, and may not always be linked to diabetes outcomes, which – according to the principles of self-efficacy and outcome expectancies
in Bandura’s SCT [8,20] – diminishes the chance of individuals initiating or maintaining these behaviours. The relatively recent diagnosis of T2DM of the participants in our study population may have contributed to the lack of intervention effects found in diabetes-specific self-care, as daily glucose monitoring [34] and daily foot checks are not generally recommended by the Dutch guidelines for all T2DM patients during the early phase of illness [35,36]. Finally, the already low baseline level of diabetes-related distress in our study sample left hardly any room for improvement by the intervention. On the other hand, as low levels of diabetes-related distress in recently diagnosed T2DM patients have previously been (partly) attributed to underestimation of the condition and not being sufficiently engaged in diabetes self-management [1], the unchanged low levels of distress in our study might indicate that illness perceptions and self-management behaviours have been targeted ‘in the right manner’, i.e. without causing additional distress. Finally, despite our focus on recently diagnosed T2DM patients’ perceptions and beliefs as a starting point for behaviour change, no significant intervention effects were found on patients’ illness perceptions and attitudes. Partly, this may have been due to our rather homogenous study population not showing a large variety in illness perceptions for the participants to mirror themselves to and change their beliefs as a result. The short-term changes in exercise and diet among the course participants may therefore be considered a direct result of the homework assignment of the third course session - in which participants were instructed to work on the goals and action plans they had developed - rather than resulting from changed illness beliefs; although it should be noted that trends were found in patients perceiving their condition to be more serious after participation in the course. Moreover, feelings of empowerment increased after participating in the course, which has been shown to be positively related to improved self-management [37–39].

Our experiences during the pilot and recruitment phase of the RCT confirmed that motivating patients for participation in a self-management support intervention in the early phase of T2DM might be particularly challenging [1]. This was reflected in the rather low participation rate, and the many patients indicating not to be interested in participating in the programme due to the (still) mild nature of their condition and/or the absence of complications or other diabetes-related problems. Furthermore, during the pilot of the intervention, it became apparent that this type of interactive group-based self-management support may require some degree of diabetes-related uncertainty in patients in order to meet their needs. As a result, a screener was developed to exclude patients who reported to manage their condition already very well and who did not experience any worries or uncertainty regarding their condition and its treatment. We are aware that application of the screener might have filtered out also those patients who underestimate their condition and overestimate how well they are dealing with it. However, our experiences during the pilot also taught us that this particular group is really difficult to motivate for active participation in the course, particularly in goal-setting and action-planning. Therefore, we preferred to exclude these patients from participation in the RCT, as they may have hindered the active participation of others in the course.
Methodological considerations

Study population
The Living with diabetes course was targeted at T2DM patients in the first years of illness, as we believe this is the phase where patients are still incorporating the condition and its treatment within the other goals and priorities that make up their daily lives, and where they have also already encountered challenges and barriers in doing so. An additional reason for focusing on this patient population was the assumption of self-management being extra challenging in the absence of diabetes-related symptoms or complications, for this often causes patients to underestimate the importance of engaging in this. A primary aim of our intervention was therefore to get patients to recognise that their condition could potentially have serious health consequences, and that self-management makes sense to diminish the changes of these complications, while the other two interventions of the Diacourse study focused more on how to deal with the physical and emotional consequences associated with diabetes-related complications. However, as was shown by the baseline data of the Diacourse study, the presence of complications was not as proportionally associated with illness duration as hypothesised beforehand. In our study population with a diabetes duration of one to three years, already one quarter of the participants indicated the presence of one or more diabetes-related complications, which was found to be related to different ways of perceiving and managing their condition. We therefore believe it might have been more suitable to distinguish the different phases in T2DM on the basis of the presence or absence of complications, or on the type of treatment, rather than on illness duration in itself.

Generalisability
For this study, we were able to reach a large and varied population of T2DM patients in their first years of illness. General practices in six different regions all across the Netherlands participated in this part of the Diacourse study. Also, since all patients in the Netherlands are registered with a general practice within the Netherlands, and all costs for participation in the course were covered for the participants, there were no patient groups excluded from participation beforehand. It should, however, be noted that only ten percent of the invited patients agreed to participate in the study. Furthermore, lower educated patient populations, who are known to be more prone to unfavourable health outcomes in diabetes [40–42], have been shown to be underrepresented in diabetes group-support [43], and it seems plausible to assume that this patient population may also not have been adequately reached by our study. As no single intervention is likely to be able to appeal to an entire patient population, targeting and tailoring self-management is of importance, as well as offering different types of support alongside each other.
**Outcome measures**

In this study, we decided to focus on so-called patient-reported outcomes, including self-management and quality of life, to determine effectiveness of the intervention rather than on clinical outcomes, such as glycaemic control. One drawback that should be mentioned in this regard, is the lack of available instruments to adequately capture the broad and multidimensional nature of diabetes self-management and diabetes-related quality of life at the time of the study. To assess (changes in) self-management behaviours, we used the Summary of Diabetes Self-Care Activity (SDSCA) [44] measure, which assesses lifestyle and self-care behaviours in diabetes (physical activity, diet, monitoring behaviours and smoking). Two important aspects of self-management, being communication with health care providers and coping with the social and emotional consequences of diabetes [45], are not covered by this instrument. Even though diabetes-related distress and empowerment – as assessed by the PAID and the Dutch DES-20 - somewhat cover (emotional) coping with diabetes and its treatment and consequences, a self-report questionnaire that properly covers all aspects of diabetes self-management and is sensitive to change over time was – and probably still is – not available.

We included the Problem Areas in Diabetes (PAID) scale, which assesses diabetes-related distress, as an indicator of patients’ quality of life. Since distress is only one aspect of quality of life, we were unable to draw conclusions about the effects of the intervention on other aspects of quality of life. On the other hand, it should be noted that diabetes-related quality of life measures are supposed to be better able to pick up changes over time than more generic quality of life measures, and we had chosen the PAID because of its known responsiveness to interventions [46,47]. However, considering the limited focus of the PAID combined with the already low baseline levels that we found in many of the study participants, it might have had added value if we had included other, multi-dimensional measures of quality of life as well. This would have allowed us to study the effects of the intervention on participants’ quality of life in more detail.

**The Diacourse study consortium**

We believe that the collaboration between Nivel, Amsterdam University Medical Centers, location VUmc, and Utrecht University medical center was a major strength of the study. The Diacourse study consortium consisted of researchers with various professional backgrounds, including general practitioners, epidemiologists, health scientists, and health psychologists, whom all sought to find effective strategies to support T2DM patients in the many challenges they encounter over the course of illness. This multidisciplinary team provided the valuable opportunity to combine the different perspectives and expertise that are needed to cover all the medical, behavioural, emotional and social aspects that make up the (daily) self-management regimen for type 2 diabetes. Furthermore, the mutual development of the studies on the three different support programmes allowed us to study a large and varied study
population, as datasets could be combined due to the alignment of the data collection and primary endpoints of the different studies. This provided us with the opportunity to examine diabetes self-management over the course of illness and check whether our underlying assumptions for the three separate interventions were correct.

**Implications for clinical practice**

Two important lessons that were learned during the study were that 1) a brief CMS-based intervention can effectively and positively change self-management behaviours, but only in the short-term, and 2) motivating patients to participate in these type of group-based self-management support intervention during the first years of illness seems to be challenging. These two findings suggest that interventions to alter illness perceptions and support diabetes self-management might be more successful when its elements are incorporated within regular diabetes care, rather than being offered in addition to this. In this manner, (almost) all T2DM patients can be reached and be offered long-term and regular self-management support. It is important that health care professionals are aware of the important role they have in this respect and that they have been sufficiently trained to explore and discuss patients’ perceptions and behaviours. We believe that regularly exploring and discussing patients perceptions towards their illness and treatment is an essential part of good-quality diabetes care, all the more because new information, skills and behaviours are less likely to be adopted by individuals when these are not compatible with their already existing illness beliefs [48,49]. In doing so, health care professionals should, however, keep in mind that they ask about patients’ perceptions of their own condition and treatment, as these perceptions may differ from patients’ perceptions of T2DM in general. Also, health care professionals need to be aware that, when discussing the impact of T2DM, they often tend to focus on future well-being, while people with diabetes emphasise the impact of the demands of diabetes management in the present [50,51]. Therefore, diabetes-related goals ideally take both short- and long-term gains and demands into account, and are integrated within other goals and activities in patients’ daily lives. Furthermore, more prolonged guidance may be needed in order to establish sustainable behavioural change in patients, which could be established by incorporating proactive goal-setting and action-planning within the three-monthly check-ups that T2DM patients in the Netherlands have with their diabetes or practice nurse.

Our findings indicate that supporting self-management should be tailored to the specific challenges that are encountered in living with T2DM. Differentiating between patients with and patients without complications might particularly be warranted, considering the differences found in the way they cognitively, behaviourally and emotionally manage T2DM. Several studies and psychological models – including the CSM [52,53] and Health Belief Model (HBM) [54,55] – stress the importance of both perceived seriousness and perceived (personal) controllability as important determinants for patients’ (motivation for) self-management. The shift towards T2DM being perceived as more uncontrollable in the presence
of complications may therefore undo the potentially beneficial effect of perceiving T2DM a more serious condition, which also often happens when complications appear. In patients without complications, health care professionals may therefore need to specifically underline the serious consequences of T2DM and the necessity to engage in self-management to prevent these, while patients with complications should rather be supported in regaining (perceived) control over the T2DM.

**Implications for future research**

We have argued that tailoring interventions to different illness phases, or perhaps even life phases, is important to increase participation in and effectiveness of diabetes self-management support interventions. In order to be able to properly tailor interventions to T2DM patient populations with different needs for support, more insight is needed in the differences in effectiveness between patient subpopulations, which calls for subgroup analyses. As mentioned before, one could imagine that the intervention might have had different effects in patients with complications than in patients without complications, considering these subgroups already perceived and managed their condition differently prior to the intervention. The presence of diabetes-related complications being a wake-up call for many patients to take their condition seriously and invest time and effort in self-management brings us to the next challenge that should be further investigated. Since one of the primary objectives of diabetes management is to prevent complications as much as possible, one of the major objectives in diabetes self-management research remains to find successful ways to help patients understand the importance of self-management before diabetes-related complaints arise. A similar challenge in which more insight is still needed is how sustainable changes in lifestyle and health behaviours can be achieved by self-management support interventions, in particular in patients who need to change (life)long maladaptive behavioural patterns, and when effects of behavioural change take a long time to become visible to individuals. Finally, we believe that future research should focus on developing questionnaires that can both capture the multifaceted nature of diabetes self-management and quality of life, and be sensitive to change over time. Both qualities are required to be able to properly judge whether support interventions have an effect on the several dimensions that make up self-management and health-related quality of life, instead of just on self-care behaviours and distress.

**Conclusion**

Patients with T2DM need lifelong self-management support, which should be tailored to individual needs and preferences that may change over time. Self-management support should differ over the course of illness, as patients appear to perceive and manage their condition differently when they have complications or are on insulin treatment. In the absence of complications, T2DM and its consequences are generally underestimated and, consequently, motivating patients for self-management (support) in the early phase of T2DM is challeng-
ing. Self-management support that focusses on establishing adaptive illness perceptions, supporting goal-setting and action-planning and mobilising effective ways of social support in the first years after diagnosis can effectively improve T2DM patients’ empowerment and lifestyle. However, as the behavioural changes are short-lived, continuous self-management support incorporated in regular diabetes care is needed.
REFERENCES


