Summary
Being diagnosed with type 2 diabetes (T2DM) confronts patients with the challenging task of adapting to living with a chronic and progressive condition on a day-to-day basis. Despite the often asymptomatic manifestation of the condition, T2DM can result in serious complications which can have a major impact on the physical and mental health of patients. While active engagement in a multifaceted self-management regimen can diminish the risk of adverse diabetes-related health events, many patients perceive this to be a challenging task in which many barriers are encountered. Patients may also struggle emotionally with their condition and its treatment and (potential) consequences, which can – directly and indirectly - impact on their health. Finally, the progressive nature of the condition may require patients to adapt their self-management strategies over time, for instance, as a result of changes in treatment or complications. Considering that coping with a chronic disease and the lifestyle changes inherent to this are difficult for many, ongoing self-management support should be offered throughout the course of illness. We therefore developed the Diacourse study, which aimed to improve self-management and diabetes-specific health-related quality of life (i.e. diabetes distress) by 1) examining the self-management support needs of patients over the course of T2DM, and 2) developing and evaluating three self-management support programmes tailored to patients’ needs in three different phases of the illness process. In this thesis, we focused on self-management (support) during the first few years after diagnosis, which is a phase in the illness process where patients are still figuring out ways to effectively incorporate the condition and its treatment within their daily lives. Particularly challenging in this mainly asymptomatic phase of illness is that many patients do not seem to take their condition seriously and postpone lifestyle changes and self-care behaviours until diabetes-related complications appear. By targeting patients’ perceptions of their condition and its treatment and challenging the incorrect ones, and by enhancing their feelings of self-efficacy and support from close others, the Living with diabetes course aimed to improve self-management and diabetes-specific health-related quality of life in patients who had been diagnosed with T2DM for 1 – 3 years.

In the first part of this thesis, we examined the illness perceptions, self-management and diabetes-distress levels of patients over the course of T2DM. The Illness Perceptions Questionnaire Revised (IPQ-r) was used to assess the different illness perceptions dimensions that make up the personal models that individuals hold about their illness: identity, timeline acute/chronic, timeline cyclical, consequences, personal control, treatment control, illness coherence, emotional representations, and cause. Self-care, which is one of the aspects of self-management, was measured by the Summary of Diabetes Self-Care Activities (SDSCA) measure, which assessed how many days during the past week the following self-care activities were performed by patients: exercise, glucose monitoring, foot care, general diet, fruit and vegetable intake, fat intake and smoking. Diabetes-distress, which was used to assess diabetes-specific health-related quality of life, was measured by the Problem Areas in Diabetes (PAID) scale.
Chapter 2 describes the illness perceptions, self-care behaviours and their relationship in T2DM patients during the first years of illness, and examined whether these differed between patients with and patients without diabetes-related complications. Cross-sectional data from 192 T2DM patients with a known illness duration between 1 – 3 years were analysed. Findings showed that patients generally perceived T2DM as a chronic, yet controllable condition but with only minor consequences. Patients with complications, however, perceived their condition as more unpredictable and less controllable through self-care and medical treatment, and its consequences as more serious. Patients with complications were more physically active and performed foot care more often. Associations were found between perceptions of personal control and more exercise and healthier dietary behaviours, perceptions of T2DM being a chronic condition and more foot care, and between perceptions of past behaviours as a cause for diabetes and lower fruit- and vegetable intake and smoking. These study findings support previous studies indicating that, in the absence of complications, patients tend to underestimate the seriousness of T2DM and postpone lifestyle changes and self-care until complications appear. Hence, the challenge for health care professionals remains how to convince asymptomatic patients of the importance of self-management in order to prevent diabetes-related complications from occurring.

Chapter 3 discusses the relationship between the time that patients have been diagnosed with T2DM (diabetes duration) and their self-care behaviours, and the extent to which these relations are explained by the presence of complications, type of treatment regimen and levels of diabetes-related distress. Cross-sectional data from 590 participants of the three Diacourse studies were analysed. Patients with a longer diabetes duration reported to be physically active for fewer days, but to check their glucose level more frequently than patients with a shorter diabetes duration. The presence of macrovascular complications and the use of insulin partially explained these relationships with exercise and glucose monitoring respectively. The presence of microvascular complications was positively associated with foot care, but negatively with following general dietary recommendations. Finally, patients who reported higher levels of diabetes-related distress were more often smokers. Maximally 5% of the variance in self-care was explained by these models, except for smoking (11%) and glucose monitoring (37%). Even though other personal or illness-related factors than the ones assessed in this study seem to influence self-care, we do believe that tailoring support to the phase of illness - and to the presence or absence of complications in particular - might benefit patients’ self-management.

In chapter 4, the relationship between diabetes duration and diabetes-related distress was examined among 590 T2DM patients, as well as the extent to which complications and type of treatment impacted this relation. Diabetes duration was linearly and quadratically related to higher levels of diabetes-related distress in patients. This association could be explained by the presence of microvascular complications and insulin treatment, which were more often found among patients with a longer diabetes duration, and which were positively related
to higher levels of diabetes-related distress. The model containing diabetes duration, age, gender, micro- and macrovascular complications and type of treatment explained 13% of the variance in diabetes-related distress. We suggest that health care professionals pay attention to diabetes-distress over the course of illness, and particularly when microvascular complications are present or when patient use insulin to control their diabetes. However, the explained variance of 13% indicates that diabetes-related distress is influenced by other factors as well.

In the second part of the thesis, we developed an intervention aimed to support T2DM patients in their self-management during the first years of illness, and evaluated its effects in a pilot study and randomised controlled trial (RCT). Illness and treatment beliefs, which are central components in Leventhal’s Common-Sense Model of Self-Regulation (CSM), were primary targets in our intervention. Furthermore, Bandura’s Social Cognitive Theory (SCT) and social support theories were incorporated in the theoretical framework of the intervention.

**Chapter 5** describes the protocol of the RCT study to test the effectiveness of the group-based self-management support programme for relatively recently diagnosed T2DM patients and their partners. The aimed study population consisted of 160 T2DM patients from different regions in the Netherlands who had been diagnosed with T2DM between one and three years ago, and who indicated to experience some degree of diabetes-related uncertainty, as assessed by a three-item screener. The intervention group received a group-based course consisting of three monthly sessions and a booster session three months later, focusing on illness perceptions, goal and action plan setting for self-management, and social support. The control group was invited to a single educational lecture. Data were collected as baseline, (T0) immediately after the third course session (T1), and six months after the third course session (T2) and included self-care and diabetes-related distress as primary outcomes, and illness perceptions, attitudes, empowerment and social support as secondary outcomes. Multilevel analyses were used to determine the intervention’s effect. The results of our study will contribute to the still relatively sparse knowledge on the effectiveness of CSM-based intervention in diabetes.

**Chapter 6** reflects on the theoretical background of the group-based self-management programme and the first experiences obtained during a pilot of the intervention. A three-session group-based course was developed, based on principles of the CSM, SCT and social support theories. The course aimed to improve self-management and quality of life in patients by changing maladaptive illness perceptions, enhancing self-efficacy by practicing goal-setting and behavioural actions, and creating a supportive environment by discussing helpful ways of providing social support. The intervention was piloted in T2DM patients with a known illness duration between one and three years, who were selected from one general practice. Sixteen of the 74 inviting patients agreed to participate (participation rate: 22%), and were divided in two groups: one group of patients (n = 8) participating with their partner, and one group of patients (n = 8) attending the sessions alone. Data were retrieved by observation and audio-recordings of the sessions, discussion between the group leaders, and evaluation
forms filled in by the participants. Overall, the intervention was deemed feasible and suitable by the participants and course leaders. The group-based format and participation of partners was generally appreciated. The challenges encountered during the goal setting and action plan development, however, indicated that patients needed to experience some degree of diabetes-related challenges or uncertainty to be sufficiently motivated for active participation in the course, which called for the development of a screener for the RCT. The observed discrepancies between perceptions of one’s own condition and T2DM in general should also be taken into account when discussing patients’ perceptions.

In chapter 7, the immediate and six-month effectiveness of the group-based self-management support programme was evaluated in a RCT. T2DM patients (diagnosed one to three years ago) from six different regions in the Netherlands were invited for the study, of which 10% was willing to participate. Multilevel analyses were conducted on 82 patients in the intervention group and 86 patients in the control group, according to the intention-to-treat principle. The intervention group showed a significantly higher increase in physical activity and fruit and vegetable intake than the control group, although these effects did not sustain until six months after the intervention. Despite higher beliefs of diabetes being caused by chance/bad luck, the intervention group also felt more empowered to handle their condition and its treatment than the control group; a finding that was still retrieved six months after the intervention. As similar short-term behavioural effects were found in other CSM-based interventions, we believe that more prolonged support is needed to achieve more sustainable lifestyle changes, for instance, by incorporating elements of the intervention within regular diabetes care.

In chapter 8, our findings and its implications, and the methodological considerations are discussed. From our study findings, it can be concluded that self-management, and therefore self-management support needs, differ over the course of T2DM. Furthermore, it was shown that a brief CSM-based interactive course specifically aimed at T2DM patients and their partners in the early phase of illness had positive effects on participants’ physical activity and dietary behaviours in the short-term, and longer-term positive effects on empowerment. The presence of complications and type of treatment regimen should specifically be taken into account when tailoring interventions to different phases in the illness process, rather than diabetes duration. In asymptomatic patients, the challenge of self-management support primarily lies in convincing patients of the importance of lifestyle changes and self-care behaviours, while in patients with complications support should rather focus on gaining (back) feelings of personal controllability over T2DM. Some degree of diabetes-related uncertainty appears to be necessary in order for patients to be motivated to actively engage in group-based self-management support programmes that include goal-setting and action-planning. Furthermore, the link between health behaviours and outcomes in T2DM should be clear for
patients in order to motivate them for self-management. Finally, it appears that long-term changes call for long-term support by health care professionals.

The small proportion of participating patients may have had its consequences for the generalizability of the study results. Another methodological aspect of the study that should be considered is that both the SDSCA measure and the PAID only assessed elements of self-management and health-related quality of life, rather than covering the entire multifaceted constructs. Adding other multidimensional measures of quality of life would have allowed us to study the intervention’s effect more into detail, especially considering that diabetes-related distress - the aspect of quality of life we measured - was already low at baseline. One major strength of the study was the consortium between the three different research centers that allowed us combine data, as well as knowledge and experience to examine (effective strategies for) self-management.

Our study findings have resulted in some recommendations for clinical practice and future research. Considering the challenge of getting and keeping patients engaged in (long-term) behavioural changes, particularly in the early, often asymptomatic phase of T2DM, we suggest that elements of the intervention are incorporated within regular diabetes care, rather than offered additionally. Ideally, illness- and treatment perceptions, and their diabetes-related goals and their associated short- and long-term gains and pains are discussed during the three-monthly check-ups, in order to find successful and sustainable ways to incorporate the care for T2DM within the daily lives of patients, and to identify potential barriers in time. In order to properly tailor self-management support and increase its effectiveness, more insight should be gained into the effects of interventions among different patients populations, as well as into successful ways to yield long-term effects in exercise and diet. Finally, to properly assess the effects of future interventions, instruments for self-management and quality of life should be developed that are capable of capturing the broad nature of these concepts, but that are also sensitive enough to detect change over time.