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Chapter 8 - General Discussion

As stated in the introduction, the goal of type 2 diabetes care is to offer patients an integrated set of interventions in relation to life style, blood pressure regulation, treatment of lipid abnormalities, and the lowering of blood glucose levels and thereby trying to prevent, or at least delay, the onset of long term diabetes-related complications. By doing so, care providers and policy makers hope to improve patients' well-being on the long term and at the same time, lower the workloads and costs of diabetes care. Emotional factors are increasingly being recognized and may play an influential role in the treatment of diabetes. However, the interrelations between emotional status, self-care and especially glycemic control are not always considered in care protocols and are not being researched in depth.

The treatment of type 2 diabetes builds, to a large extent, on patients' daily self-care behavior, which means that patients are primarily responsible for their own treatment. This underscores the importance of a patient centered approach, in which self-management support is key. The concepts of patient centeredness and patient self-management refer to enabling patients to take control of their chronic disease, the treatment, and the physical and psychological symptoms, by letting them make their own decisions and perform self-chosen actions aimed at improving their health. This patient centered approach can be supported by diabetes self-management education programs. The increasing availability, testing, and studying of online and web-based solutions for patient centered support, opens up new possibilities of treatment options. However, it raises the question if these online and web-based solutions are successful in endorsing patient centeredness and diabetes self-management in a real-life health care setting. Research in practice settings is therefore warranted.

The aim of this thesis is twofold; first, we looked at the influence of emotional status on self-care behaviors, glycemic control, and self-management educational programs. Second, we looked at the uptake of online and web-based solutions that support patient centeredness and patient self-management. By doing so, this thesis is set out to answer the following questions:

- What is the influence of emotional status, such as emotional well-being and diabetes-related distress, on the self-care behaviors, and on the effectiveness of self-management education?
- Are online and web-based solutions capable of endorsing patient centeredness and successful in supporting diabetes self-management in routine primary care setting?

Discussion and reflection on main findings

Below, the findings of the individual chapters are discussed and put into context with the thesis questions and compared against known research. Additionally, implications for current health care and policies are discussed, and suggestions for further research are made.

The role of emotional status in diabetes self-care and diabetes self-management education

To answer the research question on the impact of emotional status on self-care behaviors, the study that is described in **chapter 2** may be informative. The outcome of this study shows that both emotional well-being and diabetes-related distress influence glycemic control directly and indirectly via self-care behaviors. Based on the study outcomes it can be concluded that the impact of emotional status on self-care

can be confirmed and appears clinically relevant. The study further uncovered gender differences in influences of emotional status, which remain poorly understood and deserve further study.

Most of the found associations between emotional status, self-care and glycemic control were also found separately in other studies. For instance, the association between mood and self-care, and diabetes related distress and self-care, were also found by Gonzalez et al. (2008, 2008) who showed that depressive symptoms predict poorer self-care behavior⁷⁸, and that mood has a stronger relationship with self-care than diabetes-related distress.¹⁸¹ The found negative relationship between mood and diabetes-related distress was also shown by Fisher et al. (2010) who reported that diabetes-related distress associated with low-mood and poor glycemic control.⁵⁴ This negative relationship between self-care and glycemic control was also found in other studies that showed that increasing exercise behavior and a healthy diet significantly improved glycemic control.^{42,182} Unlike the study described in **chapter 2**, the study of Rozenfeld et al. (2008) did find that people who adhered to their prescribed medication regimen had better glycemic control than people who did not.¹⁸³ The direct association between low mood and higher glycemic control was also uncovered in a meta-analytic review of Lustman et al. (2000).¹⁸⁴ Although these studies show similar associations as **chapter 2**, the interrelations of emotional status, self-care and glycemic control have not been tested. The Information-Motivation-Behavioral skills model of diabetes self-care (IMB) did propose self-care and glycemic control in one model, but seemed to have overlooked the influence of emotional status.⁴⁵

Following the findings described in **chapter 2** and the studies described above, we can conclude that emotional status has significant relationships with self-care and glycemic control, and that its influences are complex. These findings advocate for considering emotional status, self-care and glycemic control as interrelated constructs, rather than studying single associations. By following the proposed theoretical model of **chapter 2**, a more holistic view is created. This can help to improve diabetes care, by emphasizing the influence of emotional status in care protocols, and treating it as equally important in relationship to behavioral and medical treatment options.

The proposed model can provide a framework for further studying of emotional status, self-care, and glycemic control. Future research should focus on expanding the model with, for instance, cognitions and social support.⁴⁵ Also, further studying of the gender difference may contribute to a better understanding of the workings of diabetes, and may be important for understanding and uncovering the underlying mechanism, which connects diabetes and emotional status.

Next to uncovering the influences and associations between emotional status, self-care behaviors, and glycemic control, the influence of emotional status on the effectiveness of diabetes self-management education was researched. **Chapter 3** showed that people with low emotional well-being could benefit as much from diabetes self-management educational program as participants with normal emotional well-being. Referring back to the research questions of this thesis, this would indicate that the influence of patients' emotional status on the effectiveness of diabetes self-management education is low.

Although well-being is mentioned within the diabetes self-management educational courses PRISMA and DESMOND, these programs, like most other diabetes self-management educational programs, do not specifically target emotional

status and mainly focus on supporting self-care behaviors and improving medical outcome measures such as glycemic control.^{28,31,93,94} These programs also do not fully consider the influence of emotional status on program effectiveness.^{93,94} Diabetes self-management education programs that do consider improvements in emotional status, have shown to improve psychological outcomes and, to some extent, glycemic control.^{79,111,185} However, programs solely targeting self-management behaviors, do not seem to influence emotional status as much.¹⁵

The findings discussed in **chapter 3** can reassure care providers who refer their patients to a diabetes self-management educational course, that the emotional state of the patients is not an obstructive factor for program effectiveness on factors such as knowledge, self-efficacy and self-care behavior. A participant with low mood will most likely benefit as much from the program as a person with normal well-being. Furthermore, the emotional state itself does not seem to be influenced negatively by program participation.¹⁵ A diabetes self-management educational program might even help the patient slightly improve their emotional status, which deserves further testing. However, this may not be the case for those severely depressed, who lack the energy and motivation to join the program and be actively involved. Future research should help clarify thresholds for inclusion based on well-being scores.

Future research may want to explore the impact of emotional status on program effectiveness concerning objectively measured behavioral outcomes, and other diabetes related medical outcomes such as glycemic control. Also, long-term follow-up studies may be required to uncover the influential effect of emotional status on program effectiveness after longer time periods.

Feasibility of online and web-based solutions for supporting patient centeredness and patient self-management.

One way of uncovering feasibility of online and web-based programs for the use in real-life diabetes care, is by studying effective behavioral change techniques, which are used in existing and available online environments. **Chapter 4** describes a systematic review, which provides most commonly used and most effective behavioral change techniques for web-based diabetes self-management educational programs. By uncovering most frequent and effective behavioral change techniques within online environments for managing type 2 diabetes, the study described in **chapter 4** shows that web-based solutions that use these techniques are feasible of endorsing patient self-management in a real-life setting.

Behavioral change techniques have been uncovered and taxonomized from a wide variety of interventions used in health care, designed for coping with a range of different diseases.¹⁰⁴ For instance, Dombrowski et al. (2012) uncovered influential behavioral change techniques for weight loss interventions and found that the techniques *instructions*, *self-monitoring* and *relapse prevention* contributed most to program effectiveness.¹⁸⁶ Web et al. (2010) found that *providing information on the consequences of behavior in general*, *self-monitoring of behavior* and *identifying barriers and/or problem solving* are effective behavioral change techniques for a variety of non-diabetic web-based self-management programs. They further showed that using more behavioral change techniques increases the effectiveness of the intervention.¹⁰³ The study in **chapter 4** is the only study that uncovered behavioral change techniques within online self-management programs, used for diabetes care. The found behavioral change techniques in **chapter 4** that seemed effective for web-based use, such as *feedback on performance*, *providing information on consequences of behavior*, *barrier identification/problem solving*, can further guide

the development of future web-based diabetes self-management programs for real-life use. Furthermore, it can aid online care solutions in supporting patient centeredness and diabetes self-management and may improve program effectiveness.

For uncovering feasibility of online and web-based solutions, future studies should consider testing the effectiveness of behavioral change techniques more separately from one another. A meta-analysis of effective behavioral change techniques may provide more insight into the effectiveness of individual techniques, but may prove difficult to execute due to large combinations of techniques used within a single intervention.¹⁷⁶ Furthermore, qualitative research could further enhance the understanding of which technique makes the program more appealing, useful, and therefore more feasible.¹⁸⁷

Next, for uncovering the feasibility of online and web-based solutions for endorsing patient centeredness, the study that is discussed in **chapter 5** and **chapter 6** may provide more insight. The proposed study was primarily set out to uncover the effectiveness of asynchronized personal coaching for people who were able to use a self-management support program within a personal health record in real-life primary diabetes care. The outcomes of the study, which are described in **chapter 6**, showed that a patient health record, that was made available for people with type 2 diabetes who were treated in primary care, has the potential of reaching a large group of patients, but has difficulties with upholding use, and with positively influencing diabetes outcome measures. It also showed that web-based self-management support does not come easily, and that it requires a lot of effort from care providers, patients, and policy makers to make a personal health record feasible for supporting patient centeredness. Considering the research question of this thesis, this may indicate that an online solution, in the form of a standalone personal health record, encounters difficulties in endorsing patient centeredness and in supporting diabetes self-management in a real-life diabetes care setting.

Similar results were also found by Kim et al. (2009) who reported that usage of a Personal Health Record (PHR) by the elderly and people with a low income was low, when people have; poor technological skills, technophobia, low health literacy, and limited cognitive abilities, and when there is no personal assistance. Kim et al. (2009) further reported that people who may benefit the most, are the least able to use it.¹⁸⁸ Furthermore, a systematic review on personal health records by Ko et al. (2010) found that a Personal Health Record brought little improvements in outcome measures and reported no clear overall benefits of introducing a Personal Health Record to patients.¹⁸⁹ Additionally, Ronda et al (2013) argue that promoting a Personal Health Record without further support from care providers proved less effective.¹⁹⁰ Other studies found more encouraging results. For example, a review by Tenforde et al (2011) reported small improvements in outcomes in studies using a Personal Health Record which had additional components such one-on-one consultation with a care provider via telephone or e-mail.¹⁹¹ Furthermore, Osborn et al (2010) showed that Personal Health Records could enhance patient-care provider communication, expand access to health information, improve disease management, and improve patient outcome measures.¹⁵² Other studies found that endorsement from care providers and family members contribute to higher use, and that people who are better controlled, have higher intentions for using a Personal Health Record.¹⁶⁸

These findings indicate that to effectively support patient centeredness with an online solution, both patients and care providers may need to be enthused and educated in the patient centered approach and in utilizing a digital patient supportive environment, before being introduced to a personal health record. The disposition of care providers towards the personal health record is crucial, in which endorsement of the care provider can influence the use of a patient health record by patients.³⁹ The e-Vita project has shown that a personal health record does have the interest of patients.^{164,192} However, it cannot be assumed that patients are willing or ready, to work actively on their health, simply by using a personal health record or self-management support program. To stimulate intention formation of patients for healthy behavioral change, care providers could form intentions by targeting patients' risk awareness, outcome expectancy, and self-efficacy.¹⁶⁹ The findings in **chapter 6** further indicate that when a Personal Health Record does not follow a clear implementation theory or protocol, it will most likely be under-used by care providers and patients.¹⁷⁰

Future studies and implementation projects of personal health records should consider patient centeredness to be educated and accepted by care providers and patients, before personal health record can be introduced.²⁴ The 5A's behavioral change model (Assess, Advise, Agree, Assist, Arrange), as proposed by Glasgow et al (2000) may provide guidance to endorse patient centeredness in a health care setting.²⁵ Furthermore, the development and implementation process can benefit by following a theoretical framework, such as the Medical Research Council (MRC) framework, which describes development, pilot testing, evaluation, and implementation as crucial steps for developing and implementing complex interventions.¹⁷⁰

Where the e-Vita personal health record was mainly focused on supporting patient centeredness, the PRISMA-Online program was developed to support patient self-management and self-care maintenance behavior. The online program supports patients who already learned the principles of diabetes self-management during the group-based diabetes self-management education course PRISMA. The pilot study of PRISMA-Online, which is described in **chapter 7**, shows that online self-management support is feasible of endorsing diabetes self-management for patients in a diabetes care setting.

In general, web-based diabetes self-management support programs have shown to be effective for improving diabetes related outcomes and may be feasible for use in standard diabetes care.⁴⁰ PRISMA-Online differs from most existing online self-management programs by being integrated with a group based self-management support program, that is performed within a real-life setting.³¹ Other online programs that were also integrated into standard care, showed improvements in self-care and glycemic control.^{114,115,123} Additionally, in contrast to most other web-based programs, PRISMA-online is aimed at maintenance behavior, which is still difficult to uphold in an online environment due to attrition.¹⁰¹ However by integrating the program with the face-to-face program, the usage may be upheld.⁹⁵

The pilot study provided a new tool for self-management support, which was made available for use by PRISMA-trainers and PRISMA-participants. Additionally, the study provides a basis for the further development and testing of the PRISMA-Online program and can serve as an example for other studies that wish to integrate online self-management with face-to-face self-management programs.

Following the MRC framework, the next step after completion of the pilot study, is the additional development and testing of the online program. Importantly the care providers and PRISMA-trainers should remain involved in the development and trained in the use of the online program.^{101,168} In addition, the effectiveness of the PRISMA-Online program should be studied and evaluated in a randomized controlled trial.

Reflections on research methods

Population

The patients that were studied were mostly referred to the studies by a care provider. The initial referral by care providers may have contributed to a selection bias, in which care providers may have decided if the patient was capable of participating in the study, and thereby acted as a gatekeeper between the patients and study participation.¹⁹³ After invitation from the care provider, the patients could then decide for themselves to participate in the studies. Patients were not reminded or pressured by researchers to participate. Therefore, it is possible that only people with a higher motivation for study participation and behavior change were reached. Most of the studies in this thesis failed to reach ethnic minorities, which makes it difficult to generalize the results to more mixed populations.¹⁹⁴

Setting

All studies were performed within a real-life primary diabetes care setting. In the Netherlands most T2DM patients who have not yet developed advanced complications, are treated in a primary care setting.¹⁴¹ This may have prevented the studies from reaching patients who are not well controlled and who are experiencing complications from their diabetes.

Difficulties in associative and effect modification studies

Study designs

The used cross-sectional study design in chapter 2 does not allow for assessing changes over time. Consequently, only correlational research could be conducted, which allows for uncovering associative effects only, and not for uncovering a direction of the effect.¹⁹⁵ However, the cross-sectional designs does allow for testing a proposed model fit on data.

The effect-modification by mood that was studied in chapter 3 used a longitudinal design without a control group. A study design without control group does not allow for uncovering true effectiveness of the PRISMA self-management educational program.^{196,197} Therefore caution has to be taken for allocating differences to program effectiveness. However, the study design does allow for testing effect-modification, to uncover if the influence of well-being resulted in different outcomes.⁷⁰

Measured outcomes

The types of measured constructs in the studies of this thesis where limited. For instance, the study discussed in chapter 2 and chapter 6 did not consider cognitions or social influences, which are known to influence self-care and glycemic control, as well as self-management support.^{40,170} The outcome measures that were considered in the study discussed in chapter 3, overlooked medical and physical outcomes such as weight, glycemic control, blood pressure and cholesterol, which are known to be influenced by self-management educational programs.⁹⁴ Measuring these constructs

could have provided a more complete view of influences and effectiveness of self-care and diabetes self-management educational programs. Adding different constructs to the current study may uncover unknown interrelating and/or mediating effects.

Used questionnaires

The used instrument for measuring diabetes-related distress was the Problem Areas in Diabetes 5-item (PAID-5) questionnaire, which is a validated but shortened version of the PAID-20.⁵² In the PAID-5, not all construct of the PAID-20 are measured in full extend. For example, the PAID-5 is less suitable for measuring treatment related problems and support related problems.⁵⁸ Therefore, one can argue that we cannot generalize the results in relation to treatment and support related problems, which could have influenced our results. However, the PAID-5 questionnaire was chosen so it would be less of a burden for patients to fill-in.

In multiple studies, the patients' mood was measured with the World Health Organization Wellbeing Index 5 items questionnaire (WHO-5). It should be recognized that the WHO-5 measures emotional well-being by positively stated questions, and initially does not measure depressive mood or clinical depression.⁵⁶ However the WHO-5 questionnaire has been shown to be suitable for uncovering low mood, compared to the Patient Health Questionnaire (PHQ-9).⁵⁷ For measuring of solely depressive mood, other questionnaires, or a clinical diagnostic interview may be more suitable, such as the PHQ-9, or the Center for Epidemiologic Studies Depression Scale (CESD).^{198,199}

The SDSCA self-care questionnaire asks about self-care behavior of the past week, thereby relying on the patients' recollection of self-care behavior rather than the true (actual) self-care behavior. Additionally, it is argued that the SDSCA lacks association with glycemic control compared to other self-care measurements.²⁰⁰ However, the responsiveness of the questionnaire, with which it is capable to distinguish differences over time, is high.⁶⁰ To measure true self-care behaviors, more objective measurement tools are desirable. Alternative ways of measuring self-care could be done by real life sensors in the form of wearables such as a smartphone. For example, the accelerometers in the smartphone could be used as an indicator for physical activity, and photograph diaries with the use of smart phones' camera could help measure diet adherence.^{201,202} Pill counters and blood glucose meters could be used for measuring medication adherence.^{203,204} Apart from costs and complexity, however, all these measure still fall into the honesty of the patient. If the patient does not follow the protocol correctly or wants to hide certain outcomes, this is still possible.

The Illness Perception Questionnaire (IPQ) which was used in the study discussed in chapter 3, was a shortened version which only measured 3 dimensions (coherence, control, and consequences) instead of the 5 dimensions (coherence, cause, time-line, consequences, control) of the original IPQ questionnaire.²⁰⁵ Therefore the used shortened version may not have measured the cognitive representation of the illness as proposed in the original IPQ. The internal consistency ($\alpha=.61$) was lower than reported for the original questionnaire ($\alpha=.81$).⁸⁵ This would mean that the combination of questions is not fully measuring the same construct, and may therefore be less useful to be used as sum score.²⁰⁶

Difficulties in studies of online and web-based programs

Study designs

The randomized controlled trial of the e-Vita personal health record that is covered in chapter 5 and chapter 6 was nested within a longitudinal cohort study. Furthermore, the study was testing a sub-part of the e-Vita platform, which in itself has not been pilot tested, or tested on effectiveness. Although the RCT resulted in null-results, the nested RCT study would have made it difficult to generalize the effectiveness of coaching and the possible differences between groups, in relation to the effectiveness of the e-Vita program.

The Pilot study of PRISMA-Online, which is discussed in chapter 7, allowed for testing and adapting of the program. However, feasibility, fidelity and acceptability are subjective concepts that are mainly based on the opinions of the participants and the researchers, and are therefore difficult to objectify.²⁰⁷

Program development, piloting, evaluation, and implementation

The development, piloting, evaluation, and implementation process of the e-Vita Personal Health Record followed a different path than for instance proposed by the MRC-framework.¹⁷⁰ The development phase was followed by the implementation phase, after which piloting and evaluation was conducted. This made it difficult to change components, or add additional features within the Personal Health Record, which may have hindered further development and may have limited research.

PRISMA-Online followed the MCR framework more closely. First, the needs of the care providers and participants were considered after which a theory and behavioral change techniques were selected. The program was then developed by creating, testing and evaluating the components before they were deemed complete. Next, the program was implemented into the routines of a few PRISMA-courses, and piloted for feasibility and evaluated. The next step is to adjust the program according to the pilot evaluation and test the effectiveness in a randomized controlled trial.

Attrition

The attrition rates of the intervention studies may have hindered the effectiveness testing of the interventions.¹⁰¹ However, the attrition rates is an outcome in itself, and can be relevant information for uncovering feasibility and success of online and web-based solutions for endorsing patient centered care and self-management.

External validity

The online programs were implemented and tested in standard primary diabetes care. This ensured that the target population was reached, which adds to the external validity of the studies. As mentioned earlier, it has to be noted that participants of the study described in chapter 5 and chapter 6 were slightly older people, all from the north-eastern region of the Netherlands, and contained little to no ethnic minorities, which makes it more difficult to generalize the findings of the study.

For the inclusion of participants of PRISMA-Online, the age of the participants was more spread and the program was more successful in attracting people with an ethnic background. Furthermore, participants in the group course were able to decide for themselves to use PRISMA-Online. This resembles a real-life setting which adds to the external validity.

Final remarks and future perspective

Clinical implications

Considering the research question on the impact of emotional status on self-care behaviors, and on the effectiveness of diabetes self-management education, we now know that emotional status is complex and interrelated with self-care and glycemic control, but that it does not seem to interfere with the effects of diabetes self-management education, which seems potent enough to overcome these influences. Clinically this could mean that emotional status should be considered as being of equal importance to purely medical objectives and outcomes, but also that care providers need not worry about the negative effect of emotional status on self-management education effectiveness. However, we should remain cautious when clinical depression is present.

This thesis also provides insight in the feasibility of online and web-based solutions for endorsing patient centeredness. We now know that web-based self-management support is feasible, but that support for patient centeredness via online or web-based solutions does not come easily or naturally. Clinically this means that the implementation and adoption to online solutions for patient centeredness and self-management supports requires involvement, willingness, and dedication from both the care provider and the patient.¹⁶⁸ To reach these goals, care providers as well as the patient should be educated and where necessary enthused for patient centered care, and patients should be stimulated for increasing intentions and motivations for healthy behavioral change, before introducing them to online or web-based tools.

Recommendations for future research

Future studies towards the influences of emotional status should consider using more objective measurement tools for measuring self-care. Additionally, measurement tools for measuring the concepts of mood and diabetes-related distress should be carefully selected from a vast variety of questionnaires to support the goal of the research.

Studies concerning online and web-based solutions should consider using a structured approach, in the form of a model or theory, for evaluating program development, testing and evaluation. Following the MRC framework, studies should start with development based on theory, pilot test the developed concept on feasibility, fidelity, and acceptability, then evaluate the program, and finally implement the online or web-based solution, after which the process of (re)-development, piloting, evaluation and implementation continues.¹⁷⁰ Furthermore, the study protocol should stimulate patient centeredness by providing step-by-step instructions for care providers for how to implement patient centeredness in their daily routines, before testing effectiveness of web-based and online solutions for supporting patient centeredness. The 5A's behavioral change model as proposed by Glasgow et al (2000), may be useful for endorsing patient centeredness in diabetes care.²⁵

General conclusion

This thesis was set out to uncover the influences of emotional status on self-care, and to investigate the feasibility of online and web-based solutions for patient centered care and self-management support. The findings discussed in this thesis contributed to better understanding of the complex interrelations of emotional status with self-care and self-management support. The thesis further showed that online

and web-based solutions might be feasible for supporting patient centeredness and diabetes self-management. However, online solutions have to follow a methodological approach for implementation, need to fulfill patients' wishes and needs, and receive the endorsement of care providers, to be feasible for use in a real-life diabetes care setting.

