Social relations and diabetes

Creating a support system for people with diabetes

Mitchell Kesteloo

Social relations and diabetes

Creating a support system for people with diabetes

by

Mitchell Kesteloo

to obtain the degree of Master of Science
at the Delft University of Technology,
to be defended publicly on Wednesday March 3, 2021 at 14:00 PM.

Student number:	4291158	
Project duration:	April 17, 2019 – March 3, 2021	
Thesis committee:	Dr. Ir. W.P. Brinkman,	TU Delft, supervisor
	Dr. M. Bruijnes,	TU Delft, daily supervisor
	Prof. Dr. M.A. Neerincx,	TU Delft and TNO
	Dr. J.J. Kraal,	TU Delft

Preface

This thesis was completed as part of the Computer Science master at TU Delft. Throughout the writing of this report, I have received a great deal of support and assistance.

First of all, I would like to thank Merijn Bruijnes, my daily supervisor. Your knowledge of the field helped me get to where I am know. I will surely miss our meetings where we not only discussed our work, but also laughed a lot. I would also like to thank Willem-Paul Brinkman, who supervised this project. Without your comments, this project would not have come this far. Thank you for the weekly meetings in which we all could discuss our work.

Furthermore, I would like to thank Nele and Franziska, PhD candidates in the interactive intelligence group. I hope you have some use for the tutorial I wrote about Rasa and wish you both good luck in your research.

I would like to acknowledge the other students in our group for their comments during, and sometimes outside, our weekly meetings. In particular, I would like to thank David for being there to complain about Rasa, Mohammed and Jeffrey for the nice talks after our meetings before the pandemic hit the Netherlands, Siyu for discussing our projects and our statistical analyses plans and last but definitely not least, Pascal. Without Pascal, I would have no one to exchange the perfect memes with.

Without friends, I would not have gotten this far: Lars, I'm glad you are always ready to pick up the phone and just talk for a bit. Thank you for being an awesome friend! Doris, thanks for organizing the DnD nights, which helped me stop stressing about my thesis. Thank you Remco, Axel and Emilie for just listening to me, it must have been exhausting sometimes. Sven, thank you for just chilling in Delft and Rotterdam with me. AQ, thanks for the phone calls and your interest you showed in my work.

Finally, I would like to thank my family. Without my mother and grandmother, I would never have reached university, let alone finish a master's degree. Thank you both for raising me and supporting me through all those difficult times. I hope I can repay you someday. Dad, thanks for teaching me to always give my best. Yvonne, Anton and Marijn, thanks for listening and supporting me. Lastly, Annelou, thank you for everything, hope to be able to go on a nice holiday with you soon!

Mitchell Kesteloo
Delft, February 2021

Abstract

People with diabetes often show symptoms heavily associated with depression, but these symptoms are often caused by the burden of daily diabetes management. The negative feelings caused by this burden are defined as “diabetes burnout”. Some of these negative feelings are caused by social issues. People with diabetes often resort to online sources to find out how to deal with these social issues since health care providers do not focus on this side of diabetes. Furthermore, the social stigma surrounding treatment for mental problems stops people with diabetes from going to a psychologist. In this project, a conversational agent is designed, implemented and evaluated to investigate whether it is capable of reducing social diabetes distress. The agent was designed to give personalized tips based on a social issue the person with diabetes shares. A longitudinal experiment was done over three sessions to evaluate the agent. The results show that the agent is able to reduce the diabetes distress more than a plain textual delivery of tips. The successful application shows the value of conversational agents and provide a basis to deploy such conversational agents in the e-mental health domain. The design we created can be used in future work, where a further personalized approach and a tool measuring the personalization should be investigated in order to better understand why the conversational agent is able to reduce the diabetes distress.

Contents

1

Introduction

> *Low, angry, frustrated. Everything. Because, you know, sometimes you're frustrated because the doctor hasn't told you what you want to hear. Or you're angry with the world, and you take it out on your children, your partners, everybody. And then you've got the depression that takes you down, because you're just thinking one thing after another* [47].

Diabetes patients not only deal with physical problems, but mental and social problems as well, as seen in the quote above. This quote also shows that the social environment will be impacted by diabetes and, vice versa, will have an impact on the patient:

> *Because we're talking about food; I mean, I go to my family, and when I say I can't eat that food, they usually think that's disrespecting them, so you've got all that as well to deal with* [47].

In this thesis report, a support system is designed and implemented in order to support the patient in dealing with issues within the social environment.

In this chapter, the context, motivation for this research and vision will be outlined, followed by a presentation of the current situation. This will lead to the main research question. The last section in this chapter will present the approach followed in this project.

1.1. Context, motivation and vision

The number of people with diabetes is growing at an alarming rate. There were 108 million people with diabetes worldwide in 1980 [74], roughly 2.4% of the total population. Since then, this number approximately quadrupled to the number of 422 million people with diabetes in 2016 [74], now a total of 5.4% of the total population. Diabetes is a chronic disease where the body either does not produce enough insulin, which is a hormone that regulates blood sugar, or where the cells are not sensitive enough for the hormone. The disease can cause many complications such as kidney failure, loss of vision, heart or brain stroke and nerve damage. Next to these complications, the disease also has an economical impact on society, the patients and their families because of loss of jobs and higher healthcare costs.

To reduce the severity of the complications described above, a person with diabetes will have to start checking blood sugar levels and take medication depending on their sensitivity to insulin and their own insulin production. Additionally, patients are advised to start regulating their diet and, depending on the type and severity of diabetes, change other aspects of their lifestyle [1]. Having hypoglycemia (blood glucose too low, also called a hypo) or hyperglycemia (blood glucose too high, also called a hyper) and the activities related to diabetes management are visible to the social environment and will draw reactions from it. For example, as discussed in the work by Schabert et al. [57], a patient having a hypo is sometimes mistaken for a drunkard, which can lead to embarrassment. Likewise, drawing blood for checking one's blood sugar level in public can make patients feel uncomfortable when everyone is looking in their direction, especially when people start asking questions. This can negatively influence treatment adherence. In this example, patients tend to not check their blood sugar levels to avoid such a situation. In the family domain, other problems arise. Concerned partners or parents might be afraid that when the patient has a hypo or hyper no one is around who knows what to do or they might be afraid that the patient forgets to take medication [57]. This is due to the fact that the direct social environment of the patient is often not considered after diagnosis and therefore receives little to no education [73].

This thesis focuses on the design, implementation and evaluation of a conversational agent, which in this case is a textual chatbot. The chatbot will help people with diabetes to deal with various, socially related diabetes distresses.

1.2. Current situation

Since people with diabetes are more susceptible to depression symptoms [20, 56], Dutch guidelines for health care providers (HCPs) specify to monitor the patient more closely in certain situations (for example the adaptation period after diagnosis) and to refer people with diabetes to a psychologist or psychiatrist when necessary, for example when a health care provider suspects treatment inadherence is caused by motivational issues [61]. An instrument like the Problem Areas in Diabetes (PAID) scale [70] can be used to determine these underlying motivational issues. However, the social stigma around being treated by a health care provider for mental problems stops some patients to follow up on this medical advice [66]. Furthermore, the Dutch guidelines also show that people with diabetes who are referred to a psychologist or psychiatrist are often people who already deal with psychological problems [61]. However, these same guidelines also explain that people who are mentally healthy can still benefit from talking with a professional since this can solve some of the underlying issues causing treatment in-adherence [61]. In some cases, internists or GPs refer their patients to websites of different diabetes organizations. These websites often contain tips and tricks on how to deal with specific issues, but are often focused on delivering general information about diabetes, not on dealing with diabetes distresses. This makes it hard for people with diabetes to find the information they really need. Lastly, social issues caused by diabetes are often not even on the radar of the health care provider because their focus is on diabetes care.

The technology proposed in this project is a conversational agent, in this case in the form of a textual chatbot. Since a chatbot can provide anonymous support, the social stigma barrier can be broken down. Another advantage is that this chatbot can specifically focus on social issues, something often overlooked by health care providers because of their main focus on the physical aspects of diabetes. Furthermore, it can give tips specific to the situation of the person with diabetes instead of having a big list of tips as can be found on diabetes organizations' websites.

1.3. Research Question

This project addresses the following research question:

> *Is it possible, and what is required, to use a conversational agent to help people with diabetes deal with social diabetes distresses?*

To answer this question, several sub-questions are formulated which are answered in the coming chapters. First of all, an analysis is made on what kind of distresses people with diabetes may encounter. Secondly, literature is investigated in order to find techniques which are already used for dealing with these distresses. After retrieving this domain knowledge, two focus groups are organized: one with people with diabetes and their close social environment and one with health care providers. These focus groups are organized in order to find out about possibilities on where and how to use the conversational agent. With this information, a conversational agent is designed, implemented and tested. This leads to the following sub-questions:

SQ1 *What kind of diabetes related distresses are encountered by people with diabetes?*

SQ2 *What techniques are available to help people with diabetes deal with social diabetes distresses?*

SQ3 *What are the requirements for a conversational agent supporting people with diabetes in dealing with social issues that may cause social diabetes distress?*

SQ4 *How can a conversational agent provide support for people with diabetes?*

SQ5 *Does the conversational agent provide support for people with diabetes?*

1.4. Approach

To design the system in a structured manner, the basic principles of the situated cognitive engineering (SCE) approach [44] are followed. SCE is specifically used for tasks where human-machine collaboration is central. The approach is iterative: requirements are clarified whenever new knowledge is gained by testing the prototype or by closely involving domain experts in the design and development process. In this project, the approach is applied in a more waterfall-based style due to some limitations: a longitudinal study where the target group is observed during prototype testing is not possible in the time set for this project. Instead, the aim is to do one thorough iteration so that future researchers may build upon this iteration. However, before implementation, several iterations are done to refine the requirements.

The first step in the SCE approach is to analyse the domain knowledge, the target group and the proposed technology to understand where the technology can possibly be of use. After this step, the next phase is to draft some scenarios and present these to people with diabetes and their social environment in a focus group. These scenarios are also used in a focus group with health care providers. This data is then used to determine the requirements which will be implemented. After implementation, the conversational agent is evaluated. This process is visually shown in Figure 1.1.

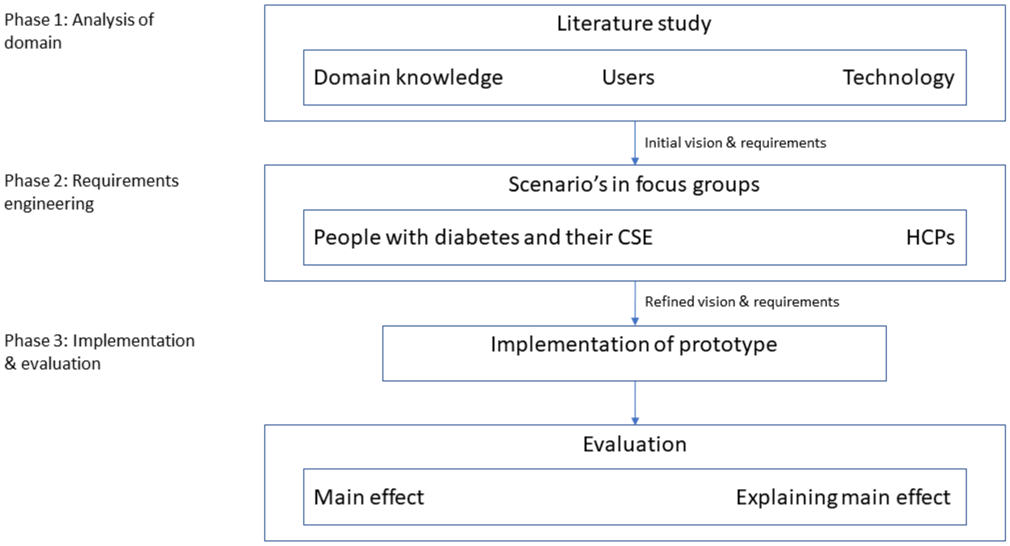


Figure 1.1: Phases of this project

The analysis of the domain, target group and the proposed technology (phase 1) is discussed in Chapter 2. Phase 1 gives a foundation for the answers to SQ1 and SQ2. The resulting knowledge then leads to the start of phase 2.

In phase 2, the scenarios that are drafted are based on the knowledge gained in phase 1. The scenarios present a diabetes-related social problem and a solution to that problem to find out what solution would be preferred. The scenarios are drafted in such a way that participants can also give input on the presented social problem so they can give an in-depth, personal view on the problem. This may possibly lead to additions to the knowledge gained from phase 1. Phase 2 is described in Chapter 3, where SQ3 is answered.

In phase 3, the requirements engineered in phase 2 are implemented and evaluated. The implementation details are discussed in Chapter 4 and answers SQ4. Chapter 5 presents the variables used in the evaluation of the chatbot, the procedure of the experiment and the analysis plan. In Chapter 6, the results are presented and provides an answer to SQ5. Finally, in Chapter 7, a discussion is presented on the project with possible directions for future work.

2

Related Work

This chapter discusses the literature study which is done to obtain domain knowledge, knowledge about the target users and knowledge about possible technology uses. This corresponds to phase 1 as shown in Figure 1.1.

The first step is to gain an understanding of the distresses experienced by people with diabetes within their social environment. Furthermore, it is important to know what the current situation of treating diabetes distress is to find possibilities for where to deploy the technology. The current situation also gives some information regarding existing strategies and their effectiveness of dealing with diabetes distress. The diabetes-related distresses are presented in Section 2.1 and the strategies to deal with these distresses are presented in Section 2.2.

The second step is to find possible uses for conversational agents. These findings are presented in Section 2.3. Conversational agents in the health domain bring some ethical dilemmas to the surface, which are investigated afterwards in Section 2.4. Lastly, Section 2.5 presents the initial vision and requirements for the conversational agent. This knowledge is then used to create scenarios for two focus groups in Chapter 3. The information acquired in this phase forms the basis for answering "*What kind of diabetes related distresses are encountered by people with diabetes?*" (SQ1) and "*What techniques are already available to help people with diabetes deal with diabetes distresses?*" (SQ2).

2.1. Defining diabetes distress

The different types of diabetes distresses are presented in Section 2.1.1. Finally, this section presents the answer to "*What kind of diabetes related distresses are encountered by people with diabetes?*" (SQ1).

2.1.1. Negative feelings associated with diabetes and measuring these feelings

People with diabetes have a higher chance of developing symptoms of depression [20]. However, it has been found that depression symptoms are different for people with diabetes than other people because the symptoms are heavily associated with the burden of daily diabetes management [23]. The negative feelings people experience caused by the burden of daily diabetes management are defined as 'diabetes burnout' [50].

Since these feelings are heavily associated to the daily management of diabetes, many researchers have investigated how to detect whether people with diabetes suffer from any of the negative feelings associated with diabetes burnout. Polonsky et al. created the Problem Areas in Diabetes (PAID) survey [51]. This instrument is still used today to find out whether people with diabetes experience negative feelings caused by diabetes. There are numerous other instruments as well, for example the ATT39 [19] and the QSD-R [27]. However, these instruments, including PAID, have some limitations. The different underlying constructs causing the negative feelings for people with diabetes are either barely encompassed or not included into the instrument at all. Furthermore, evaluating the PAID survey is done by checking the questions individually. When one of these questions indicate that the person with diabetes suffers negative feelings caused by diabetes, a conversation is started with the person with diabetes. Using sub-scales to see what type of diabetes distress is experienced is preferred for clinical purposes: the sub-scales can be used to determine the underlying cause of the negative feelings associated with diabetes. ATT39 and QSD-R do provide these sub-scales, but are instruments with many items, where less items are preferred due to the time it takes to fill in a longer questionnaire. In addition, it takes more time to evaluate a longer questionnaire.

To accommodate the need for a complete, concise instrument, Polonsky et al. [52] presented the "diabetes distress scale" (DDS). This survey measures four diabetes distresses: regimen distress, emotional burden, interpersonal distress and physician stress. Since the population used for testing the DDS were mostly type 2 patients, Fisher et al. [23] investigated DDS for type 1 patients. This research showed seven sources of distress for type 1 patients: powerlessness (feeling of no control over diabetes, fear of future complications), management distress, eating distress, hypoglycemia distress, negative social perceptions (fear of getting treated differently by others), family/friend distress and physician distress.

Comparing the DDS for type 1 (T1) and type 2 (T2) patients, the differences lie in the fact that, for T2DDS, distress caused by the different parts of treatment is in one group, while type 1 patients experience the multiple facets of their regimen as different types of stress. Furthermore, T1DDS clearly shows that type 1 patients may also experience distress from hypoglycemia, something more common in type 1 patients. However, the instruments share many of the questions, although some of these questions are categorized into different distresses.

2.1.2. The different distresses for people with diabetes

From the above, an answer to "*What kind of diabetes related distresses are encountered by people with diabetes?*" (SQ1) is formulated, although some additions may be made in Chapter 3 if the focus group generates new insights. People with diabetes may experience distress from hypoglycemia, interpersonal relationships, having to manage their diabetes, relationships with health care providers, negative social perceptions, the feeling of being powerlessness and eating distress. It is important to note that during the process, one of the initial ideas was to also involve the close social environment. Therefore, we have also investigated which people are involved in the day-to-day management of diabetes, defined which of these actors belong to the close social environment and we have investigated diabetes distresses for people belonging to the close social environment. However, the scope of this project was later redefined: we only focus on people with diabetes. Therefore, this background information for the social environment has been moved to Appendix A.

2.2. Strategies to cope with diabetes-related distresses

This section presents what health care providers do to support people with diabetes and whether there are any solutions available to support them. This is done to answer "*What techniques are already available to help people with diabetes deal with diabetes distresses?*" (SQ2). We also investigated what techniques there are to help the close social environment deal with diabetes distress. However, the scope of this project was later redefined: we only focus on the people with diabetes. This information is therefore moved to Appendix A.

2.2.1. Strategies for people with diabetes

There are many strategies for a person with diabetes dealing with diabetes-related distress, but other than the standard procedure of treating a person with diabetes, there is no standard strategy which health care providers apply to deal with diabetes distress. When someone is diagnosed, they first get some training which covers dieting, what medication to take and how to take it (an insulin dependent person with diabetes gets training on how to inject) and how to measure blood glucose levels. Generally, after diagnosis, usual care consists of quarterly meetings with an internist, a GP or a specialist nurse where average blood glucose levels (HbA1c) are discussed along with other issues like stress or how to diet. Furthermore, patients are sometimes referred to another specialist when necessary. Figure 2.1 shows what this process looks like in the Netherlands.

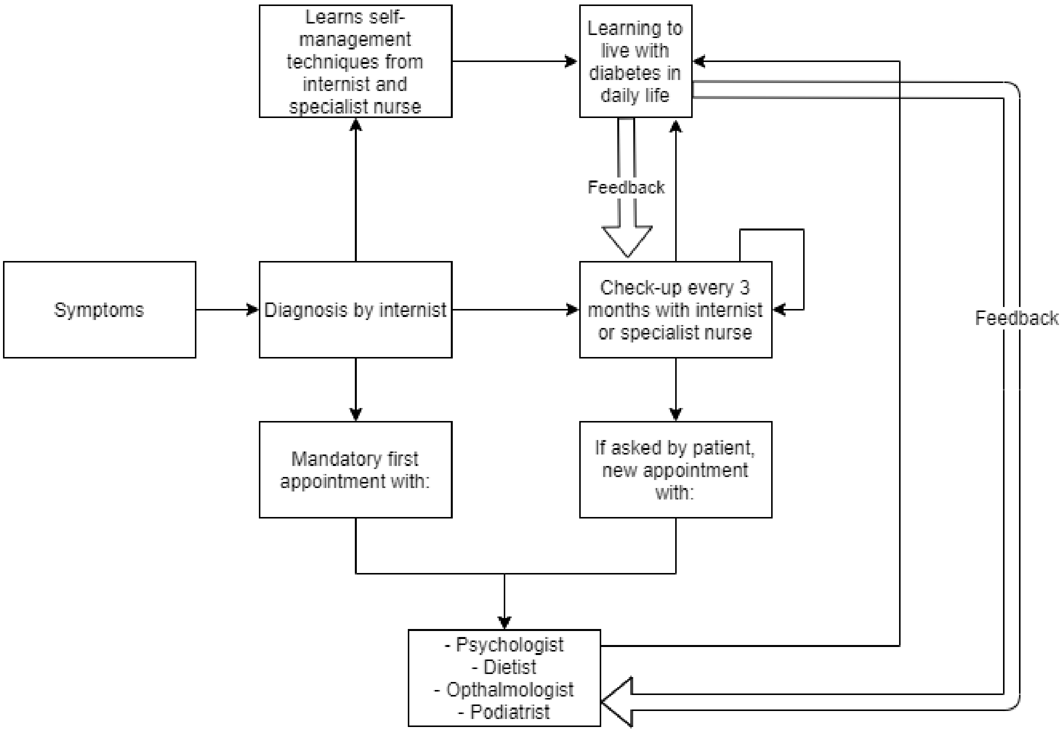


Figure 2.1: The process of diagnosis

In this process, there are few contact points with the health care provider and the contact itself is short. The information provided by health care providers during the quarterly meetings often has a focus on diabetes care. During the process depicted in Figure 2.1, the strategy that health care providers use to help patients deal with diabetes distress is monitoring and based on what they see, educate the person with diabetes. A study by Snoek et al. [62] showed that simply monitoring psychological well-being by letting a person with diabetes fill in a questionnaire before a consultation and discussing the results during the consultation might already help in reducing diabetes distress for people experiencing negative feelings associated with diabetes. The research does state that, since the data collections was done over multiple countries, there was no standard path for referring a person with diabetes to another health care provider, for example a psychiatrist in case the person with diabetes shows signs of depression or diabetes distress. It is also unclear how the data from the questionnaires is used to start discussing it with the person with diabetes.

Next to the usual care, which are the quarterly meetings with the health care provider where diabetes care and lab results are discussed in the Netherlands, researchers have tried to find other methods to battle diabetes distress. A recent systematic review of psychological interventions for people with type 1 or type 2 diabetes by Schmidt et al. [58] assessed whether psychological interventions tailored to diabetes are more helpful than regular psychological interventions such as mindfulness training or cognitive behavioral therapy (CBT). The psychological interventions investigated in this systematic review were mindfulness training, health-coaching and group-based training. For some of these interventions, motivational interviewing is used to achieve change. With motivational interviewing, a counselor helps the patient explore why a certain wanted behavior is beneficial and tries to resolve ambivalence. The counselor does not instruct, but rather helps the patient explore. Motivational interviewing was also used in the research by Keogh et al. [32] where someone from the close social environment was included in an intervention for better blood sugar control. Motivational interviewing has also been used in the design of conversational agents, for example to persuade the user to exercise more often [59]. The papers reviewed by Schmidt et al. [58] were investigated to see how the interventions were built up. From the nine included papers, three had no to little information on the used intervention itself.

From the other six, one was a mindfulness-based intervention not specifically tailored to diabetes. The resulting five interventions [31, 36, 45, 55, 71] were analyzed in detail to find possible requirements for the conversational agent. We found that all interventions were longitudinal. Three of the interventions [31, 36, 55] start with a session where the participant's individual problems are discussed. Based on this information, tailored advice is given to deal with these problems. These three interventions actively engage the participant by for example asking them to come up with potential solutions to their problems and discussing advantages and disadvantages of solutions. This active engagement is part of Shared Decision Making (SDM) [13], in which patients are actively involved into making decisions about treatment.

As evident from the limited number of included interventions in Schmidt et al. [58], more research is needed to determine what kind of intervention works for all type 1 and type 2 patients. The research by Schmidt et al. does include a meta-analysis: it presents that most research on psychological interventions do not have diabetes-related distress as a primary outcome, indicating the need to investigate other interventions with a focus on diabetes distress. The results show that interventions not focused on diabetes do not cause improvement regarding HbA1c (average blood glucose value over the last 2 to 3 months), but diabetes-specific psychological interventions do have a positive effect on the HbA1c. However, this positive effect was found to be bigger in this systematic review than in two other systematic reviews by Chew et al. [14] and Sturt et al. [63], where the positive effect was found to be significantly smaller. This difference might be explained by the fact that both reviews did not account for baseline differences and did not exclude people who have zero to little diabetes distress in the meta-analyses.

Lastly, a search is done for strategies available directly to the person with diabetes. This is done because the interventions discussed above all involve an external party and are not easily available. There are many self-help books available. One of these books is “Diabetes Burnout” by Polonsky [50], which contains tips for people with diabetes on how to deal with the different forms of diabetes distress. For example, the book gives some assertiveness strategies to readers to use in challenging social situations, gives some tips on how a person with diabetes can educate the close social environment and gives tips on how to organize support for oneself. The book is backed up by scientific research. Another way of finding help for dealing with diabetes distress are the many diabetes fora, blogs, vlogs and other information available online. However, the source of the provided information on these platforms is often not reported, making it hard to determine whether this information is reliable.

2.2.2. Interventions for dealing with diabetes distress

With the above sections, an answer to “*What techniques are already available to help people with diabetes deal with diabetes distresses?*” (SQ2) is formulated. The limited number of research focused on interventions for dealing with diabetes distress show that more work is needed. We did find some similarities in these papers, including actively engaging the person with diabetes (element of motivational interviewing), educating over multiple sessions and tailoring the education to the problems the person with diabetes has. We also found that psychological interventions specifically tailored to diabetes-related issues are found to work better than usual care. These findings also give us the first requirements for the conversational agent:

- **R1:** The agent should be able to find out what the underlying issue is when given input by the user
- **R2:** The agent should provide the person with diabetes with information on how to deal with social diabetes distress
- **R3:** The information the agent will provide should be personalized to the situation of the person with diabetes
- **R4:** The interaction between agent and person with diabetes should be spread over multiple sessions

2.3. Conversational agents in health

Since recent years, commercial use of conversational agents is rising. Probably the most famous examples are Amazon's Alexa, Google Assistant and Apple's Siri. There are however many more examples. The following use cases show the diversity of applications which chat interfaces provide [60]:

- Conversational commerce: instead of searching by typing or making a list for grocery shopping, just type what you need at that moment and it will be ordered for you
- Increasing productivity in business by for example scheduling appointments for the users
- Personal coaching and monitoring tools
- Alert or notification bots
- Bots as routers between humans: if a user want to speak to someone who can offer a certain service, a bot is a great way to redirect the user to that person[1]
- Customer service and FAQ bots
- Third party integration bots in order to improve productivity
- Games and entertainment
- Brand bots: since almost everyone has a chat app on their phone, this is easier to use for users than installing an additional app

Using conversational agents in health is done more frequently as evident from the amount of research in this area. An example of a chatbot focusing on mental health issues is Woebot which uses CBT to improve mental health [24]. This research showed that delivering CBT by using Woebot improves mental health. The participants of this research, however, were on average around age 22, so it is not clear whether delivering CBT to people of older age is also effective. Another example of a conversational agent is designed by Bickmore et al. [8]. This conversational agent is designed to promote exercising and a healthier diet to users by having a simulated conversation. The conversations contain elements of motivational interviewing and social cognitive therapy. The agent is available via a user's personal computer. Many other examples exist: a comprehensive overview of the latest uses of conversational agents in health is provided by Montenegro et al. [41] and Callejas et al. [12]. The latter overview also presents conversational agents used for applying therapy, self-management, intervention and counselling successfully. This suggests that a conversational agent designed to support people with diabetes is a viable option.

2.4. Ethical considerations using conversational agents

Using conversational agents in health raises ethical questions. These agents may be used to give health advice or are sometimes used as complete replacement of a health care provider. In this project, the conversational agent is not a replacement, but it gives advice based on input of the user. The agent does talk about potentially sensitive topics such as the user's diabetes distress. In addition, conversational data is stored which potentially contains personal data. Therefore, we examine ethical issues in this section.

To touch all areas where potential ethical issues might rise, research by Kretzschmar et al. [35] is used. This research proposes to consider the following three areas which are considered to be the "minimum ethical standards" for conversational agents:

1. Privacy and confidentiality
2. Efficacy
3. Safety

These areas will therefore be investigated in the next subsections to make sure that, during the design of the conversational agent, these ethical standards are taken into consideration.

---

[1] See for example Sensay: `https://www.kik.com/bots/sensay/`

2.4.1. Privacy and confidentiality

Data should be protected in order to keep up with GDPR regulations and to make sure that data is kept confidential. In this project, this means considering conversational data and any answers to questionnaires. This data might contain sensitive topics regarding health. Therefore, it is crucial to make sure this data is either stored securely or not stored at all. If the conversational agent is designed in such a way that it stores patient data, GDPR regulations should be carefully analyzed to minimize risks. To further ensure privacy and confidentiality, personal information should be anonymized whenever data is accessed or shared, for example to improve the technology. This is one of the privacy-protective measures the GDPR recognizes. To further ensure user trust, being transparent about what happens with the shared data is a must. One of the initial ideas was to create a conversational agent that interacts with the person with diabetes and the close social environment. The agent would be able to share information about the person with diabetes with the CSE whenever the person with diabetes wants to. However, the Human Research Ethics committee advised to not do this because of the sensitivity of health data. Therefore, we decided to only focus on a solution targeting the person with diabetes.

Regarding the delivery of the conversational agent, a stand-alone piece of software developed in-house would mean that there is no third party involved which might get access to the user's data. This is why conversational agents like Wysa and Woebot provide a stand-alone app. However, integrating with WhatsApp or Facebook Messenger is preferred regarding usability because users would not have to install an additional app [60]. It might also be hard for the patient to ask someone to install an additional app since this might reinforce stigma. In this case, since the aim is not to make the agent available to the general public immediately, a chat application that can run on the TU Delft server is used. The above leads to the following requirements:

- **R5:** Data ownership should not be shared with external parties and safely stored on a private server
- **R6:** The conversational agent should be available in a clear, easy-to-use chat interface

2.4.2. Efficacy

Kretzschmar et al. [35] states that users should know what the chatbot actually targets and how it tries to achieve its goal. Furthermore, the research states that the conversational agent should be tested empirically to show that the conversational agent is actually able to make a difference. As an example, Woebot [24] has a website explaining the used intervention and presents information about the research behind Woebot. Kretzschmar et al. [35] states that just providing such a page might not be enough. The research also states that the conversational agent itself should also be able to answer questions like "How can I be sure you will help me?" to make sure people who do not read information beforehand are still able to see that the conversational agent is evidence-based. Since this project does not immediately aim to release the conversational agent to the general public, these worries do not apply yet.

2.4.3. Safety

Regarding safety, users should be aware that they are not talking to a human, but to a piece of technology [35]. Bickmore et al. [7] also shows that this is an argument against using conversational agents if the user is not made aware of this fact: Laura, a relational agent used by older adults, is given the appearance of a cartoon character to show the user it is definitely not a person. Laura also frequently reminds the user that she is just a chatbot and does not have the capabilities humans have. Even if the user is aware that the conversational agent is not a human, it can still be ethically questionable: according to Pickard et al. [49] participants with age averaged 25 prefer revealing sensitive information to conversational agents over revealing to humans. This finding might be misused if a creator of a conversational agent has immoral intentions.

Furthermore, giving health advice might be dangerous if done incorrectly. Bickmore et al. [9] showed that commonly used conversational assistants like Siri, Alexa and Google Assistant are often used to search for health advice, even though they are not designed for this task. In the research, these agents were assessed on their health advice. The results show that patient might receive harmful advice and, in some cases, following this advice would be fatal. For this project, giving incorrect health advice regarding medication use is dangerous: advising to inject insulin for example might be lethal in certain circumstances. Therefore, another requirement we have is the following:

- **R7:** The conversational agent should not give advice on the use of medication

Using a chatbot as a first line care giver or even as a complete replacement implicates that such a system should give the same level of safety as a human care giver would. In these situations, conversational agents should have systems in place to deal with emergency situations. The system should follow the safety procedure which a doctor would follow when needed. However, research by Tielman et al. [66] investigated safety procedures for e-mental health systems and the report shows that these safety procedures are often under specified and have more resemblance with a rough guideline open for human interpretation. This also holds for the guidelines provided by the Dutch General Practitioners Society (NHG) for diabetes type 2 patients [1]. This makes it hard to implement these safety procedures into the design of a conversational agent since implementing rough guidelines open to human interpretation in a software system is challenging. In this project, the conversational agent is an addition to the usual care and is not designed to be a partial or complete replacement of health care provider.

Lastly, the effect of using a conversational agent on a longer term has, to our knowledge, not been investigated yet as research by Morris et al. [42] points out. It is not yet clear whether users would for example start preferring emotional support from conversational agents over support from their family and friends and, if that happens, what that would lead to. This might mean missing important interactions and might endanger the user. To counter this, the research by Kretzschmar et al. [35] suggests that conversational agents might include dialog which aims to encourage users to seek human support or to give users tasks to complete together with others. We do not aim to let participants use our agent for a very long period, meaning we do not expect our users to develop relations with our agent so deep that they start preferring it over their family and friends.

2.5. Initial vision

An initial vision for the conversational agent is created with the information above. The instruments used to measure diabetes related distress contain separate sub-scales for socially related diabetes distress. We focus on creating a solution which helps people with diabetes with socially related diabetes distress. Existing research shows that interventions most effective for dealing with diabetes distress are interventions tailored to address diabetes-specific issues. However, the limited number of research into these interventions do imply more work is needed to effectively determine what (factors of) interventions work best for this population and in which situation to apply these interventions. We did find similarities between the interventions we investigated: actively engaging the person with diabetes (an element of motivational interviewing), treating the person with diabetes over multiple sessions and tailoring the information to the situation of the person with diabetes. Tailoring information to the personal situation of the person with diabetes is done by finding out what problems the person with diabetes currently faces and, based on those problems, give advice. By treating the person with diabetes over multiple sessions, the advice can actually be used by the person with diabetes and an evaluation is possible on how the advice worked or not. The above leads us to the following requirements for the conversational agent:

- **R1:** The agent should be able to find out what the underlying issue is when given input by the user
- **R2:** The agent should provide the person with diabetes with information on how to deal with social diabetes distress
- **R3:** The information the agent will provide should be personalized to the situation of the person with diabetes
- **R4:** The interaction between agent and person with diabetes should be spread over multiple sessions

The amount of successfully deployed conversational agents for therapy, self-management, therapy and counseling implies that a conversational agent is a viable option in supporting people with diabetes to deal with social diabetes distress. These agents are often deployed on existing platforms such as Facebook Messenger since users are not required to install any additional software and are already familiar with the platform. However, using conversational agents in the health domain means potentially handling sensitive information. Therefore, a piece of software created in-house is the best option to ensure data ownership stays with the TU Delft. Lastly, we investigated the potential dangers of giving health advice. With our target group, giving incorrect advice on medication use is potentially lethal under certain circumstances. Therefore, we do not give any advice on medication use but focus on the social side of diabetes. the above leads us to the following, additional requirements:

- **R5:** Data ownership should not be shared with external parties and safely stored on a private server
- **R6:** The conversational agent should be available in a clear, easy-to-use chat interface
- **R7:** The conversational agent should not give advice on the use of medication

3

Focus group

Phase two, as shown in Figure 1.1, is presented in this chapter. Two focus groups were prepared and carried out in order to further increase domain knowledge and to possibly refine the requirements for the conversational agent. These requirements are then used for the design and development of the prototype.

For the preparation of the focus groups, a presentation is made containing a set of scenarios. Each scenario is followed up by at least one claim which is presented to fire up discussion. This is done to give some structure to the discussion. Section 3.1 presents the different scenarios used in the focus groups and the reasoning behind using these scenarios. The organization of the focus groups is discussed in Section 3.2 to show how participants are recruited. Section 3.3 shows the results of both focus groups. Lastly, Section 3.4 concludes this chapter and presents the refined requirements to be implemented.

Before presenting the information, it is important to note that the focus group and the literature study were done simultaneously. The initial idea was to include the close social environment of the person with diabetes. However, the scope was changed in a later stage of the project since the Human Research Ethics committee (HREC) of the university advised not to do this: sharing health data, even among the close social environment, is considered to be too sensitive as explained in Section 2.4.1. The focus group therefore has a big part focused on this idea of sharing data between person with diabetes and close social environment. The information retrieved from the focus group scenarios focused on this idea still has value: it is able to validate our findings from literature and is a potential future research direction. Therefore, this information is presented in this chapter.

3.1. Creating scenarios

The goal of the focus groups is to further refine the requirements as presented in Section 2.5. Therefore, potential solutions meeting these requirements are presented to the participants in order to find out whether such a solution would work. We also want to investigate whether participants would trust a conversational agent with their data, especially when they know that the agent might use this to send personalized tips based on this information. Therefore, the presented solutions should also reflect this data exchange in order to find out what kind of data participants would or would not share and when they would share that data. Another objective was to find out whether people with diabetes would share information with the chatbot when they knew that the chatbot will potentially share this information with the close social environment. Lastly, the scenarios also contain different settings regarding social problems in order to elicit reactions about social problems and potentially get more insight into the social problems encountered by the person with diabetes. Participants of the focus groups are asked to discuss on the topics above. The scenarios for the focus groups should give some structure to this discussion.

With these objectives in mind, the following scenarios are created:

- **Scenario 1:** a party in a close social setting and a party with a more distant social group. Patients often have to deal with unhealthy food or drinks and sometimes just eat/drink it in order to avoid difficult questions, which may cause a hyper. Participants are asked whether they would use a conversational agent for these different social groups: letting the agent share data with people you know very well might be easier for the person with diabetes then sharing with people with whom the relation is more shallow. The objective is to find out whether people with diabetes would still use the chatbot when the chatbot shares information with different social groups.
- **Scenario 2:** a student at high school dealing with difficult/confronting questions. Two strategies are presented. The first strategy shows a situation where the conversational agent is available to the social environment. The social environment can use the agent to ask questions about the person with diabetes, for example about the symptoms of hypoglycemia. The second strategy is to let the person with diabetes practice a conversation with the agent, where the agent acts like someone asking difficult questions. This teaches the person with diabetes how to deal with these questions. The goal is to find out what strategy participants prefer.
- **Scenario 3:** tension in the close social environment caused by a patient who tends to forget to bring her medication. In this scenario, the objective is to find out whether participants would trust a conversational agent with their data, what they would share with the conversational agent and whether the conversational agent is allowed to give this information to other people.
- **Scenario 4:** as mentioned before, patients often have difficulties communicating with their health care provider, so this scenario shows a social setting where the person with diabetes gets angry with the health care provider. The questions presented to the participants are about whether they would trust a conversational agent to lead the conversation with the health care provider and what kind of strategy they would prefer.

The scenarios all share similar solutions where a conversational agent is used to assist the person with diabetes and/or the close social environment. The requirements as presented in Section 2.5 were used to make drafts of these solutions.

3.2. Organizing the focus groups

Two focus groups are organized: one with people with diabetes and someone from their close social environment and one with health care providers. The first focus group is organized to receive direct input from the target group while the second focus group with health care providers is organized to gather more insight on whether they think conversational agents are indeed an addition but also to obtain more domain knowledge.

For the focus group with people with diabetes and their close social environment, a classroom was reserved at a local high school where chairs were set up in a circle around a screen. Participants were approached by using personal connections via email. During this process, age, gender and other social- and economical aspects were considered to diversify the participants as much as possible. In order to ensure anonymity, the invitation was sent by a supervisor who was not familiar with the selected participants. The potential participants were asked to contact this supervisor when interested in participating. For this focus group, six participants were recruited of which three were a person with diabetes and three were from the close social environment of a person with diabetes.

Before beginning the focus group, all participants filled in an informed consent form. Then the focus group started with a brief introduction on conversational agents in health. After the intro, the scenarios were presented followed by one or more discussion points. During the focus group, recordings were made which were transcribed and anonymized where necessary. Participants were given a small monetary compensation for their time and effort after the focus group. The whole process described above has been approved by the HREC of the university under number 846.

The focus group with health care providers has a similar setup as the focus group with the target users. In this case, a supervisor contacted a large university medical center to set up a meeting with the diabetes team. The team consists of fourteen members: physicians, physicians in training, dieticians, a psychologist and the head of the team. The whole process described above has been approved by the HREC of the university under number 871.

3.3. Findings of the focus groups

In this section, the results of the focus groups are presented. First, the findings of the focus group with people with diabetes and their close social environment are presented. In the second subsection, the results of the focus group with health care providers will be discussed. The last subsection summarizes what is learned from the focus groups.

3.3.1. Focus group with people with diabetes and their close social environment

After analysing the recordings, five main themes were found in the discussions:

- **Stigma:** participants indicate that patients face social stigmatization, which corroborates our findings from Chapter 2. This stigmatization has negative effects on the quality of life. One participant gave an example of having fluctuating blood sugar levels at work. Colleagues asked why this happened, the participant explained that stress was involved and that this may cause the fluctuation in blood glucose levels. However, coworkers then always asked why the participant was stressed when he/she had fluctuating blood glucose levels.

  People with diabetes also encounter insensitive comments like “Do you have diabetes? But you are not fat?” or “Should you eat this? Won’t you die from eating this?” frequently. These comments might be a cry for knowledge from the social environment.

- **Ignorance:** many people simply do not have the knowledge to understand what diabetes is and how it affects the person with diabetes. To stress the importance of education, a participant gives an example where the participant was in elementary school and the class had to bake small apple pies. The participant expressed the inability to eat the small apple pie because of the carbohydrates in it. The teacher did not understand, since there is fruit in an apple pie and ordered the participant to just eat it, resulting in a hyper for the participant.

  Participants show enthusiasm for using a conversational agent to educate the general public. Introducing a conversational agent to the close social environment should not be done by the person with diabetes since that would reinforce stigma.

- **Health care provider:** participants express that they experience difficulties in their communication with the health care provider. They feel that the health care provider is too focused on the numbers, not on personal issues. Some participants are even fearful to share their personal problems since therapy non-adherence or disagreements about the treatment are all recorded in patient files. An example was given by one of the participants who uses a insulin pump with a continuous blood glucose monitoring device. The participant disconnected the pump during one night since the device beeps whenever blood glucose is too high or too low. The participant did not have a good night’s rest for over a week since blood glucose levels were not great for that period of time. This was mentioned during a meeting. During a follow-up meeting, this was mentioned by the health care provider. The health care provider told the participant that the pump should never be disconnected again. The fact that the meetings are very short does not help as well. The participants’ frustration was clear during the focus group. A conversational agent could be used to help patients prepare for their meetings with the health care provider. However, changing medical advice is not the goal since we do not possess the knowledge and we should not undermine the authority of the health care provider.

- **Social conflicts resulting from diabetes:** both people with diabetes and family members indicated that social conflicts often happen, which can be caused by mood swings when having fluctuating blood glucose levels, concern about treatment adherence, forgetting medication or about food intake. Furthermore, people with diabetes do not want to bother others when going to a social event. For example, one participant said that asking others to also bring along light soda every time feels tedious and stigma enforcing and therefore the participant just drinks water. From these comments, we see a potential to use a conversational agent to let others know to bring along light soda for social events. There is also potential in using the conversational agent to psycho-educate the close social environment to help them deal with social conflicts.

- **Information sharing:** regarding social conflicts, both patients and family members see a potential in using a conversational agent to share information instead of asking directly. For example, a type 1 patient using a insulin pump with a sensor measuring blood sugar levels could potentially be used to inform the conversational agent. People from the close social environment could then ask the conversational agent about the blood glucose levels of the patient. This might generate more understanding for the patient's behavior. With information sharing, however, privacy has to be kept in mind. One option to deal with this is to implement rules which tells the agent when to share what data and under what circumstances.

3.3.2. Focus group with health care providers

This focus group was done after the focus group with people with diabetes and the close social environment. Since we found the above five themes, an effort was made to go deeper into these five themes whenever they came up during the discussion. The following points of interest were found in the recordings:

- **Social problems are an important barrier for therapy adherence of people with diabetes:** Every participant indicated that, for all patients and illnesses, the social circle and social support is important for therapy adherence. For type 2 diabetes, lifestyle is often the cause, which is influenced heavily by the social circle. The participants gave some examples on how social problems may stop a person with diabetes to follow treatment. One person with diabetes working at a large bank indicated that disclosing she has diabetes to her coworkers would never happen since she thinks it would harm her career. This shows social stigma is indeed present. Another example is a girl who tries to have low blood glucose levels to avoid having to take insulin at school: she did not want to bring it along because others called her a "diabetes bitch". She was taken to the emergency room multiple times. The participants indicated that this also happens for type 2 patients, for example when a lifestyle change should be implemented involving family. To show that ethnic background is also a factor, the health care providers gave an example of a Hindustan mother who was always taking care of her family. She did not take care of herself simply because she was always thinking about others.

- **Social problems occur with all patients:** The participants clearly stated that every person with diabetes has social problems influencing their treatment adherence. Some factors do influence what kind of social problems are experienced. For example, certain ethnic groups have a "shame culture" where speaking about illnesses or psycho-social problems is still a taboo. The participants indicate that for type 2, social economic status is more of an influence than for type 1 as research has shown that social economic factors such as poverty and education are correlated with type 2. As an example, a person with diabetes who is in debt does not prioritize diabetes care.

  During the discussion of the treatment of social problems, the psychologist stated that it does not happen very often that someone from the close social environment is brought along. If there are issues between person with diabetes and close social environment, this is almost always only discussed with the person with diabetes. For a younger person with diabetes with type 1, the psychologist states that it is more about "raising children".

  Since social problems occur with all patients, a discussion was started on what to prioritize when looking at personalized care. Participants indicated that for personalized care, social economic status, ethnic background and personality has to be considered. For this last point, it is important to know how people deal with being ill.

- **Most important psycho-social issues:** After some discussion, a question was raised on the most important psycho-social issues. The following issues were brought up. The list is not ordered in any way.

  - Discipline: making therapy fit in life
  - Shame
  - Fear: for the future, for complications, to enter a hypo
  - Acceptance of illness
  - The influence of the social circle: how do others deal with “my” diabetes
  - Diet: for example a person with diabetes who has work related dinner does not want to stick to diet, or a person with diabetes has a hard time sticking to a diet
  - Frustration and anger: “why does this happen to me”, “why do I constantly have to deal with it”
  - Social events and social pressure: younger person with diabetes goes out, Moroccan or Turkish person with diabetes eats food prepared by their wife even if it does not fit diet
  - Ignorance or lack of understanding from social environment: for example people do not understand person with diabetes deals with diabetes 24/7
  - Personality: a structured person has less issues with diabetes
  - Self-image: people want to fit in with image of their social group, especially younger patients
  - Depression: occurs more with diabetes
  - Social economic status: low status often means higher chance of having diabetes

- **Are social agents a priority?:** Participants were asked whether they think social agents should be a priority in the diabetes care. On average, participants see it as a nice extra addition. The primary concern for the diabetes team is the direct physical issues caused by diabetes, not social problems. However, they do acknowledge that a person with diabetes with good HbA1c values and no hypos might still suffer from social problems but these are simply not on the radar of the health care provider. Social agents might therefore be an extra to help the person with diabetes deal with these social problems.

  One of the participants sketched what would be the perfect application in her view. The agent should be available 24/7, supports the person with diabetes with self-management and is capable of giving social support. An example was given of a person with diabetes going to the store for pizza. The person with diabetes can then ask the agent what pizza would fit the person with diabetes’ diet better.

  The participants do express concern about using social agents but, due to lack of time, these concerns were not explored thoroughly. Privacy was mentioned, particularly how much agents will listen in on what a person with diabetes says. Furthermore, participants expressed concern regarding existing online communities such as diabetes fora. These websites do not do enough to protect user privacy since everything is discussed openly and there is no option to log in anonymously. In addition to privacy, agents were compared to dogs detecting hypoglycemia. These dogs protect against life-threatening situations continuously. However, a social agent should not contentiously measure everything since the participants feel that this is not ethical. The participants state that users should know what happens with their data and who is responsible for it.

  The diabetes team has a clear view of the goal which the agent should achieve: making the person with diabetes more autonomous. The participants mention a research where patients with heart problems were monitored continuously. This caused patients to feel as if they got more attention by the health care provider while they had less direct contact with the health care provider than before. They see similar potential in using social agents: a continuously available agent which is able to answer questions may cause similar positive effects as the continuous monitoring tool for heart patients. As an example, the agent might be able to refresh knowledge of a person with diabetes about alcohol and diabetes. Another suggestion was to “socialize” the data generated by continuous blood glucose monitoring devices: since recognizing patterns has become easy to do with computers, they see a potential in recognizing patterns and relating this to suggestions an health care provider would make when seeing these patterns. This makes it easier for patients to understand what is happening. For example, if a hypo is coming up, give a suggestions to eat something. However, the agent should not interfere too much and become another case of diabetes police. Another concern here is that a person with diabetes might become too lazy when the agent monitors issues like hypo- or hyperglycemia continuously. It should be clear that such an agent should be a support tool, not a complete “cure”. Another possible goal for the agent might be to receive and share knowledge patients have with the health care provider: some patients have a lot of knowledge about very specific issues which the health care provider does not have.

Lastly, the introduction of the agent to the person with diabetes was discussed. The participants see a role for themselves here. They indicate that they want to remain in charge to ensure quality in the system and mention that the person with diabetes should share any advice or insight gained from interacting with the agent with their health care provider.

3.3.3. Concluding remarks on focus group results

From both focus groups a preference towards an agent used for education was expressed. The health care providers gave an example of the “perfect” agent in their opinion, which is an agent including data from continuous blood glucose monitoring devices and knowing what to say in any diabetes-related situation. It is also clear that many social problems are often caused by ignorance or a lack of knowledge, meaning education is indeed a valid option as intervention. This is already present in the requirements as presented in Section 2.5: “*The agent should provide the person with diabetes with information on how to deal with social diabetes distress*” (R2).

The focus group with people with diabetes and close social environment showed that communication with the health care provider about anything else than the primary diabetes care is difficult. People with diabetes feel that meetings are too short, too focused on the numbers and participants are sometimes fearful of sharing certain personal issues as everything is recorded. The second focus group confirmed that a health care provider’s primary concern is diabetes care and that social problems are sometimes not even on the radar. A social agent would therefore be considered an addition, since these agents might help a person with diabetes where a health care provider cannot.

Another point which is validated by the results of the focus groups is the fact that many of the psycho-social issues are caused by social relationships or social stigma. The initial idea to help the person with diabetes by educating through personalized tips seems to have potential. The health care providers do point out that personalized education is preferred by looking at the current situation of the person with diabetes, the social economic status, ethnic background and how the person with diabetes deals with being ill. In this project, we cannot look at the latter three due to ethical issues: the HREC of the university advised not to include these factors. We can look at the current situation of the person with diabetes. This information is already present in the requirements “*The agent should be able to find out what the underlying issue is when given input by the user*” (R1) and “*The information the agent will provide should be personalized to the situation of the person with diabetes*” (R3) as presented in Section 2.5.

As expected, there are some concerns when using conversational agents. During the discussions, it was stated that privacy is important and that data should be well-protected. However, due to time constraints, a further exploration of what kind of data is “shareable” with the close social environment and when to share this data was not possible.

3.4. Requirements

From the information above, the requirements as presented in Section 2.5 are validated. The data from the focus groups shows us that the initial vision is a viable option. The requirements are shown in Table 3.1 for future reference. The conversational agent should be developed in such a way that it can find out what kind of diabetes distress the user is suffering from and use the input given by the user to give personalized education. Furthermore, the agent should be capable of keeping track of current and past issues in order to be able to help the user in the future, for example when a certain issue arises again. Because of this tracking, trust should be generated by ensuring secure data storage and by providing a trustworthy chat interface.

The next chapter presents the implementation details of the requirements above.

R1	The agent should be able to find out what the underlying issue (diabetes distress) is when given input by the person with diabetes
R2	The agent should provide the person with diabetes with information on how to deal with social diabetes distress
R3	The information the agent will provide should be personalized to the situation of the person with diabetes
R4	The interaction between agent and person with diabetes should be spread over multiple sessions
R5	Data ownership should not be shared with external parties and data should be safely stored on a private server
R6	The conversational agent should be available in a clear, easy-to-use chat interface
R7	The conversational agent should not give advice on the use of medication

Table 3.1: Requirements for the conversational agent

4

Design and Implementation

This chapter presents the first step of phase 3 as depicted in Figure 1.1, namely the design and implementation of the prototype.

In Section 4.1, the design plan is presented. The design plan provides an answer to "*How can a conversational agent provide support for people with diabetes?*" (SQ4). The technology that is used is presented in Section 4.2. The purpose of this section is to explore the possibilities and boundaries of the currently available technology. Section 4.3 presents the implementation of the chatbot. The requirements as shown in Table 3.1 are used as a structure for this section to make sure every requirement was met.

4.1. Design

In this section, the design of the conversational agent is presented. First, a high level overview is given of the system. Then, an explanation is given about how the conversational agent initiates the conversation in the first session, see Section 4.1.2. Next, the second and third sessions are presented in Section 4.1.3.

4.1.1. High level overview of design

With the requirements and the information as presented in Section 2.2, a high level design was created. We have opted for having three sessions. Between sessions, we have a minimum time of seven days in order to give the person with diabetes some time to implement the tips in their daily life. In addition, people might be in different social environments during the week, for example at work and at home.

The design of the agent is based on existing interventions [31, 36, 45, 55, 71] and contains components of Shared Decision Making (SDM) [13]. Every session starts with an initiation: the agent explains what the purpose is for this session. After this explanation, the current status of the user is determined by interacting with the user. Depending on the user's current status, the agent presents the pros and cons for every appropriate strategy. With this information, the user is able to make a choice of the preferred strategy. This preferred strategy is then presented in detail to the user. During the next session, the agent will then ask the user whether the preferred strategy worked and, if not, whether another strategy is preferred. The complete process above can be seen in Figure 4.1 and is explained in more detail in the next sections.

4.1.2. Starting the conversation

The first session is about detecting the underlying social diabetes distress and giving a first tip. This corresponds to teaching the person with diabetes (formation of abstract concepts and generalizations)

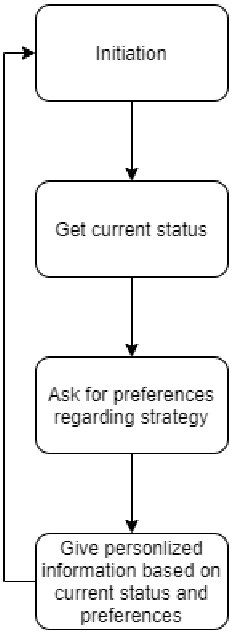


Figure 4.1: High level design of conversational agent

and persuading to testing these new knowledge (testing implications of concepts in new situations) as seen in Figure 4.5.

To start the conversation, we have looked at already existing chatbots like Woebot [24] in order to see how these existing technologies handle the initiation of a conversation. The first step of this initiation is introducing the chatbot and explaining what its purpose is. Explaining the purpose is an important step for establishing trust according to Wachtel et al. [67]: it gives the user an idea of how the treatment aims to make an impact, causing the user to set realistic expectations. This expectation management is also part of Shared Decision Making [13]. After explaining the purpose, a short explanation is given on how to use the chat interface. Then, the chatbot explains what the purpose of this particular session is. In the first session, this means explaining that the agent wants to find out what kind of social issues the person with diabetes may experience. After giving this information to the person with diabetes, the agent asks the user about the user's current situation. This is part of Shared Decision Making [13], in which information exchange goes both ways. After receiving information about the user's current situation, tips are given based on the underlying social issue. A general structure for the first session can be seen in Figure 4.2, where the new paths of the conversation are used to determine what kind of tips would work best for the person with diabetes and explaining these tips.

4.1.3. The purpose of the second and third session

The second and third session further continues in the experiential learning cycle, see Figure 4.5. This is done by first reflecting on the experience. As explained in the high level design, asking for reflection was also present in existing interventions [31, 36, 55] and is important to help the user understand why something may (not) have worked and gives an opportunity to show empathy to the user, which is an important part of Shared Decision Making [13]. After reflecting, the user may ask for more tips on how to deal with diabetes distress. This means starting with learning new concepts, a new iteration in the experiential learning cycle. The agent therefore first presents all the possible tips with some pros and cons for each tip. This helps the user make a decision on what strategy to try next. Presenting the pros and cons of a strategy is again an important part of Shared Decision Making [13] since it gives the user the option to evaluate the benefits and risks of a strategy, improving expectation management. The above leads to four main paths in the conversation, see Figure 4.3:

- **Accept rejection and ask tips:** the person with diabetes might not want to share an example because it feels to private. This can also happen in the first session. The agent explains it

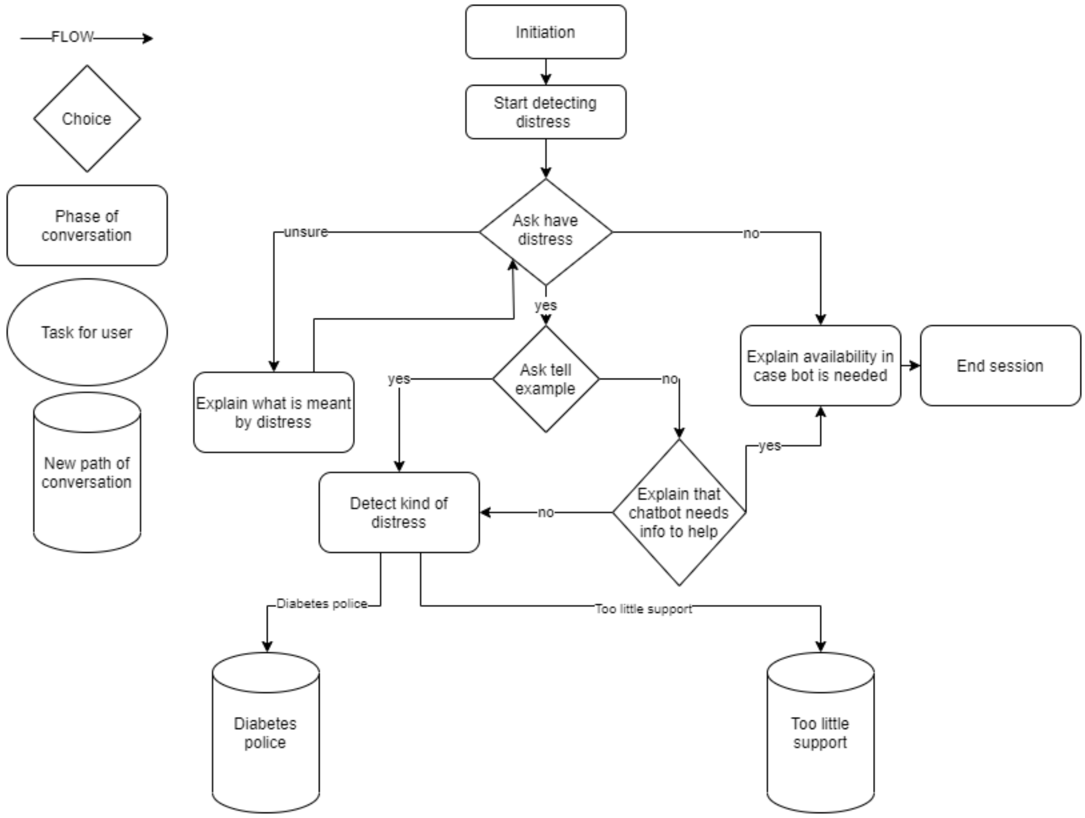


Figure 4.2: Steps of conversation in the first session

understands why the person with diabetes does not want to share something personal. In the second and third session, the agent asks the person with diabetes for tips to help others with in case the person with diabetes still does not want to share an example. This strategy was also presented in work by Tielman et al. [66]: this work showed that it might do more harm to persuade a user to go through the interaction with the agent than simply accepting the fact that the user does not want help.

- **Ask tips from person with diabetes:** the person with diabetes may indicate that there is no distress. In the second and third session, if there is still no distress, the person with diabetes is asked for some tips to help others.
- **Ask if more tips wanted:** the person with diabetes tells the chatbot the tips from last session already helped. In this case, the chatbot assumes there is no distress anymore in the next session. The agent asks the person with diabetes if there is a need for other tips and may present more tips if the person with diabetes indicates their need for more tips.
- **Explain person with diabetes tip again or use other tip:** the person with diabetes tells the chatbot the tips from last session did not help. In this case, the agent indicates that the time between sessions might have been too short, especially since some of these social issues might have been present for a very long time making it more difficult to change [50]. The agent tries to cheer up the person with diabetes and explain the tip again or give another tip based on what the person with diabetes prefers.

4.2. Technology

Since the need for conversational agents is growing, there are many tools to build your own conversational agent. However, most of these tools are focused on bringing the chatbot to an existing platform such as Facebook Messenger, Slack or Google Assistant. As discussed in Section 2.4, the use of such

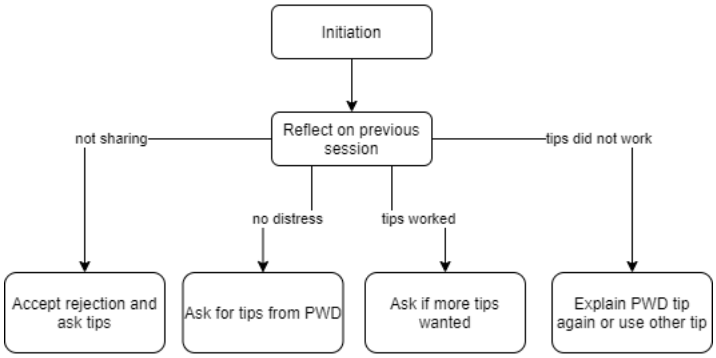


Figure 4.3: Possible directions of conversation in session 2 and 3

tools is ruled out since these existing platforms save user data on their servers.

A free, open source tool which allows the creator to save data on their own server without having to share it with the tool provider is Rasa [10]. Rasa provides a complete architecture where bot creators can quickly roll out a basic chatbot. This architecture includes an NLU pipeline, dialogue management, Rasa X (backend with GUI, ability to connect to Git repository), the ability to create custom I/O channels, a custom action server and several other services like event/conversation trackers. This architecture can be seen in Figure 4.4.

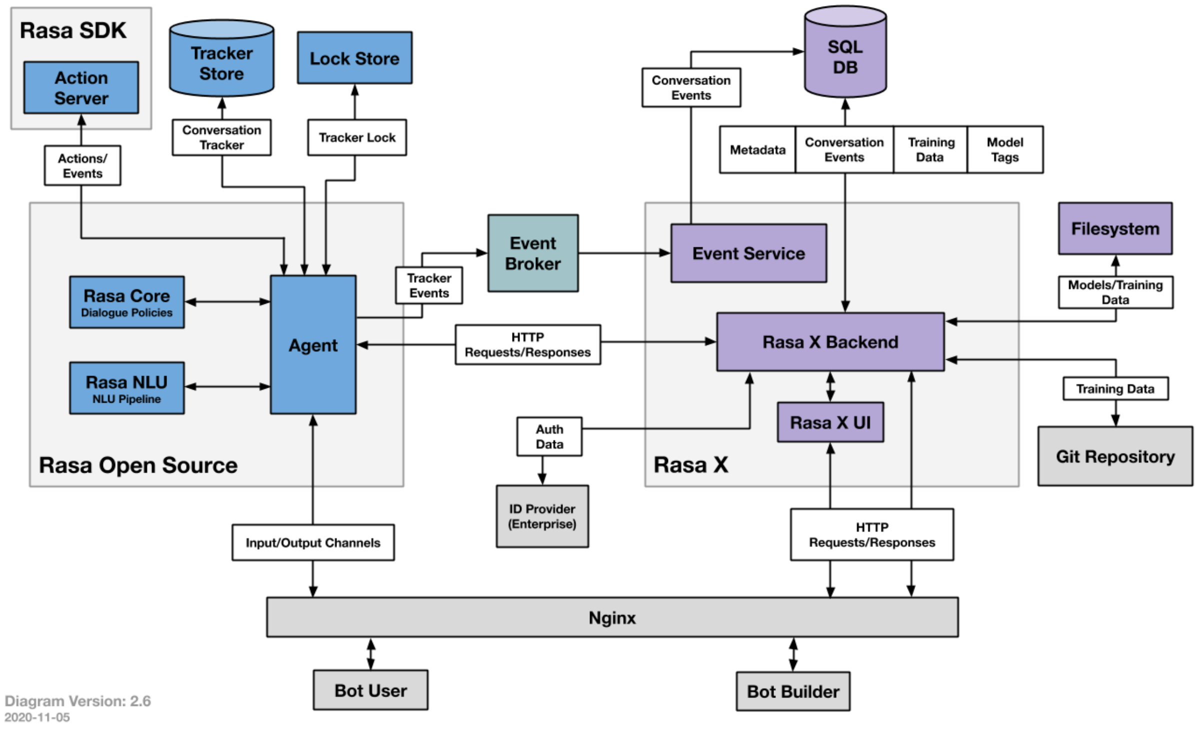


Figure 4.4: Architecture of Rasa [10]

Limitations of Rasa

Most components in the Rasa architecture can be customized. In this project, custom actions were used for making queries for updating the database and the Rasa X GUI was used for training models, managing training data and checking the conversational data. However, there are some downsides. During implementation, we first attempted to include as much open conversation as possible, allowing more personalized conversation. Rasa suggests deploying as soon as possible to generate the conversational data to train the agent on. This is called “conversation driven development”, meaning that the agent is deployed after training on a single happy path (path you expect the user to take). New stories are then added after a user has a conversation with the chatbot which deviates from this happy path. In addition, this would generate new training samples for intent classification. This, however, is often not possible in the academic field since a fully functioning conversational agent is needed to run an experiment. In addition, the agent implemented in this project needs more than one single “happy” path to function. Lastly, having many test users is costly. We noticed that creating stories to train the agent on dealing with a lot of possible directions within a conversation is not feasible in a short period of time. Therefore, buttons with dialogue choices are used to limit the possible directions in which the conversation can go. This also reduces the probability of unsuitable behavior, which Bickmore et al. [9] showed to be important for agents in health.

4.3. Implementation

The server was set up on a TU Delft machine. The standard Docker install for Rasa and Rasa X was used. We run our frontend in different Docker containers. This is done to make sure that the initiation message of the conversation is fitting for each session. The requirements, as presented in Table 3.1, are used below to make sure every requirement is met.

R1: The agent should be able to find out what the underlying issue (diabetes distress) is when given input by the person with diabetes

One of the first steps in the conversation between person with diabetes and chatbot is finding out what kind of socially related diabetes distress the participant is experiencing, see Figure 4.2. The Type 1 and Type 2 Diabetes Distress scales as presented in Section 2.1.1 show that there are three different types of social diabetes distresses: interpersonal distress, friend/family distress and negative social perceptions. As seen in the implementation details for requirement 2, we only focus on implementing interpersonal distress and friend/family distress. The interpersonal distress and negative social perceptions are classified as “too little support” since the tips retrieved from Polonsky’s book “Diabetes burnout: What to do when you can’t take it anymore” [50] gives tips for these specific situations. Friend/family distress is classified as “diabetes police”, again to refer to the tips from Polonsky’s book.

To detect the underlying diabetes distress, the person with diabetes is asked to supply an example of a social issue they experienced recently. The agent then determines the underlying diabetes distress based on the provided example: the NLU pipeline is used to train a model for determining these underlying diabetes distresses. We have created training samples for the Rasa NLU pipeline for both distresses by asking master students and PhD candidates to supply a number of examples. Roughly 50 training examples for both diabetes distresses were created. However, the number of potential issues is immeasurable. A common problem in NLP when dealing with domain specific language is creating enough examples to make sure prediction accuracy is high enough. To deal with this issue, a common strategy is to ask the user for verification. We use this strategy: the agent will ask the person with diabetes whether the underlying diabetes distress is determined accurately. If the agent was wrong, the person with diabetes is asked to elaborate on the example supplied earlier. By verifying, the agent makes sure that appropriate tips are given.

R2: The agent should provide the person with diabetes with information on how to deal with social diabetes distress

To educate people how to deal with interpersonal distress and friend/family distress, Polonsky’s book [50] is used (pages 215 - 245). This book is a self-help book for people with diabetes, covering many different aspects of diabetes distresses. The interpersonal distress questions are about the feeling that there is too little support and the friend/family distress questions are about the feeling that others treat the person with diabetes as a fragile, sick person. However, the book does not contain any tips on how to deal with negative social perceptions. Liu et al. [38] asked respondents for recommendations on how to deal with the social stigma surrounding diabetes. Increasing the general public’s knowledge about the causes of diabetes and to a lesser extent diabetes management was the most common recommendation. However, the scope of this project is to focus on the person with diabetes, so educating the general public is not an option. There are indications that people who perceive to have a high level of social support have less distress from social stigma as presented in work by Chronister et al. [15] and Mueller et al. [43], although this research was not done with people with diabetes but people with mental illnesses. Because of these indications, we consider the tips to deal with too little support (or interpersonal distress) to also be useful for dealing with negative social perceptions.

The method of education was also considered. Since we have multiple sessions, see R4 below, we implement Kolb's Experiential Theory [33]. This theory sees learning as a iterative cycle, see Figure 4.5. The main idea behind this theory is that someone can enter this cycle in any of the phases. In the conversation with the agent, the person with diabetes is shown some tips on how to deal with a certain distress, so they start by forming abstract concepts and generalizations. The agent then encourages the person with diabetes to start using the tip by explaining how the tip works, giving examples of situations where it works and motivating the person with diabetes to use it before the next session, pushing the person with diabetes towards the active experimentation phase by trying out what has been learned. This in turn leads the person with diabetes to doing an experience. In the session that follows, the conversational agent asks the person with diabetes if the tips were used and, if yes, ask how it went, making the participant reflect on the experience.

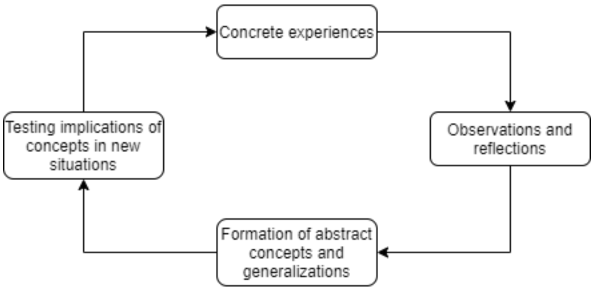


Figure 4.5: Kolb's experiential learning theory [33]

R3: The information the agent will provide should be personalized to the situation of the person with diabetes

This requirement is already partially fulfilled by determining the person with diabetes' diabetes distress and giving tips which help the person with diabetes deal with this particular distress. To further personalize, the person with diabetes is also asked whether diabetes distress is present and whether the person with diabetes feels comfortable sharing an example of a social issue. If the person with diabetes feels that there is no diabetes distress present, the agent asks the person with diabetes to help the chatbot with thinking of new strategies to deal with diabetes distress. If the person with diabetes is not comfortable with sharing a social issue, the chatbot explains that it understands that it might be hard to talk about these issues, but that it cannot help without this information. In case the person with diabetes still does not open up, the chatbot explains that it will be available when the person with diabetes is ready to open up. This strategy is somewhat similar to a strategy Tielman et al. [66] uses in a system where people are motivated to self-refer to a human care giver when an autonomous e-mental health system detects a potential risky situation but does not have the ability to auto refer the user to a human care giver. In these cases it might do more harm to persuade a user to go through some tips then simply accepting that the user does not want help. However, the chatbot asks the user if they are ready to open up during the next session. If the user is still not willing to share, the agent asks the person with diabetes to help the chatbot with thinking of new strategies to deal with diabetes distress, just like when the person with diabetes does not feel any diabetes distress.

R4: The interaction between agent and person with diabetes should be spread over multiple sessions

Spreading the interaction over multiple sessions means the state of the conversation should be saved and linked to a particular participant. We have created our own database using Sqlite, a light weight database management system.

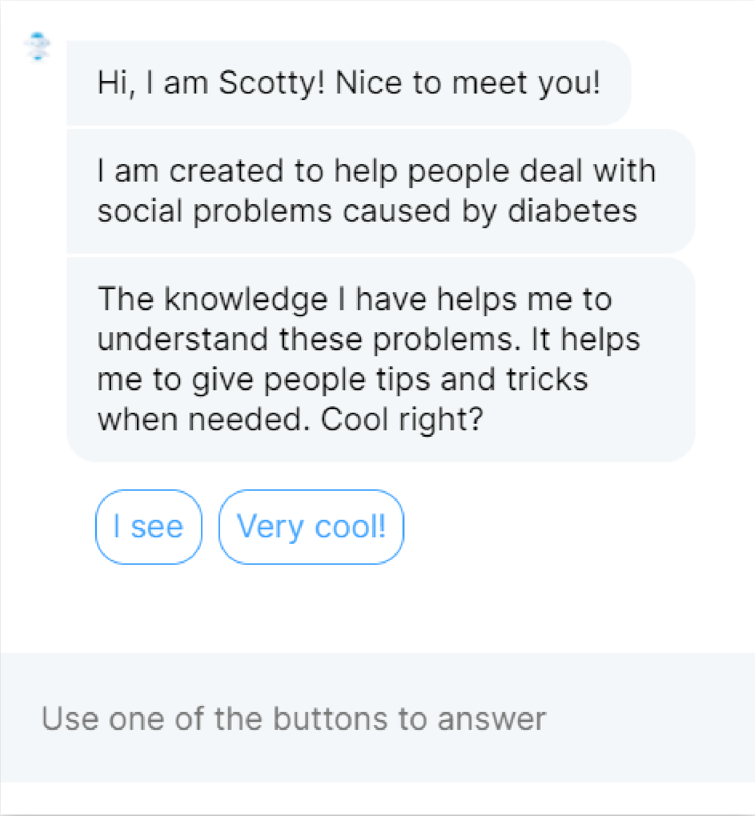
The Prolific ID of the user is used to keep track of participants. The training stories and custom action server is used to make any updates when the participant is in a certain state of the conversation. For example, when a person with diabetes indicates that there is too little support for the person with diabetes, the custom action server creates an update query which is then executed. In the next session, the agent is able to retrieve this data from the Sqlite database and start the session accordingly.

R5: Data ownership should not be shared with external parties and data should be safely stored on our server

By using Rasa, any conversational data is stored on a TU Delft machine without sharing it with external parties. The survey data is stored on the researcher's TU Delft account on Qualtrics, an external survey tool. After running the experiment, the Prolific IDs are removed and replaced with other random IDs and any data files are stored on the 4TU Center for Research Data. The above has been approved by the Human Research Ethics committee of the university under number 1130.

R6: The conversational agent should be available in a clear, easy-to-use chat interface

The Rasa Webchat[1] widget is used to deploy the chatbot on the TU Delft server. The interface is similar to existing platforms like Facebook Messenger, see Figure 4.6. If open text is expected, participants can type in the text box at the bottom of the page. Otherwise, they can use buttons with dialogue choices under the last message sent by the chatbot.



Hi, I am Scotty! Nice to meet you!

I am created to help people deal with social problems caused by diabetes

The knowledge I have helps me to understand these problems. It helps me to give people tips and tricks when needed. Cool right?

Figure 4.6: Interface used during experiment, initiation of first session

---

[1] `https://github.com/botfront/rasa-webchat`

R7: The conversational agent should not give advice on the use of medication

This last requirement is important because giving wrong advice about using medication can be fatal for a person with diabetes, like shown by Bickmore et al. [9]. The Rasa answer templates used by the agent do not include any answer options where an advice on (not) using medication is given. The agent solely focuses on dealing with the social diabetes distresses.

5

Evaluation setup

In this chapter, we present how the conversational agent is evaluated. This is part of phase 3 as shown in Figure 1.1. We first present the experimental design in Section 5.1, where the conceptual models are also presented. Section 5.2 presents the measures we used. With the measures and conceptual models, an experimental procedure was created, see Section 5.3. The analysis plan is presented in Section 5.4. With the information in this chapter, a foundation is made for answering "*Does the conversational agent provide support for people with diabetes?*" (SQ5).

5.1. Experimental design

The experiment has a between-subjects design and is double blind. Participants were randomly assigned to a "social help program": the control group or the agent group.

This social help program is our independent variable, see Figure 5.1. The participants assigned to the control group receive a plain, textual delivery of the strategies used to deal with social diabetes distresses based on tips retrieved from Polonsky's book "Diabetes burnout" [50] (pages 215 - 245). The participants assigned to the agent group receive these strategies by interacting with the conversational agent. The control group is an approximation of the current situation. In the current situation, the health care providers have a focus on diabetes care, not on helping the person with diabetes deal with social issues. People with diabetes are often referred to websites of diabetes organizations to search for tips. In some cases, they are referred to a psychiatrist/psychologist. However, there is a stigma associated with going to one of these health care providers [66]. Therefore, we compared the impact of the agent on the diabetes distress difference with the impact of a plain, textual delivery of the tips on the diabetes distress difference. This simulates having a person with diabetes search the internet for tips on how to deal with social diabetes distresses and comes close to the current situation. The same text is presented to the control group over three sessions, where participants are asked to read any information useful for them for a minimum amount of time (at least 30 seconds). The participants in the agent group interact with the agent over three separate sessions as well.

The goal of this project was to support people with diabetes to deal with diabetes related distresses within their social environment. To answer this question, the difference between diabetes distress before interacting with the social help program and after interacting with the social help program is used. This diabetes distress difference is our dependent variable as seen in Figure 5.1. We hypothesize that this diabetes distress difference is influenced by the social help program. As explained above, people resort to online sources to seek help for dealing with diabetes distress in the current situation. We expect that the agent feels more personal since it asks the person with diabetes what kind of distress the person with diabetes has and gives one or several tips based on that. Furthermore, it asks whether the tip worked and why (not) in the second and third session, trying to improve the application of the tips or giving another tip to the person with diabetes. This improves upon the current situation since there is no personalization of information when searching on the internet and there is no explicit feedback loop, both important factors of Shared Decision Making [13]. The above leads to the following hypothesis, visually shown in Figure 5.1:

- **H1:** People using the conversational agent have a larger reduction in diabetes distress than the control group

We aimed to explain why the difference in social help program has an effect on the diabetes distress difference. The difference between the social help programs can be found in the design. The agent tries to be empathetic, considers user preferences and provides information based on the current status of the user: the components of Shared Decision Making [13]. These components are not present in the social help program for the control group. We hypothesize that the attitude towards the social help program depends on the type of social help program the person with diabetes is exposed to. According to Petty et al. [48], attitude encompasses three elements: affective (feelings towards an object), cognitive (beliefs and perceptions of an object) and behavioral (responding to the object). We think that the agent influences these three elements positively, while we expect that the plain, textual delivery does not have this positive influence on the attitude. The attitude is considered to be a mediator as seen in Figure 5.1. To make this concrete, the following hypothesis was formulated:

- **H2:** The effect of the social help program type on the diabetes distress difference is mediated by the attitude towards the social help program

When a person with diabetes has little or no distress, the social help program will not be able to make a big impact on the diabetes distress difference, simply because there is little or no room for improvement. Different investigations have been made into the prevalence of diabetes distress for both T1 and T2 diabetes. These investigations tend to draw different conclusions on what “high” distress is and use different tools to measure diabetes distress. For example, Gahlan et al. [25] reports 18% of the investigated population consisting of T2 patients have diabetes distress. A more recent work by Beverly et al. [6] reports other statistics: 27% of T1 patients and 30% of T2 patients indicated to have high distress (≥ 3). This last research defines moderate distress as a diabetes distress score between 2 and 3, but does not report the percentage of people with moderate distress, making it difficult to determine how many participants have little to no diabetes distress at all. Therefore, we decided to include the pre-measurement diabetes distress as a moderator in our conceptual model, see Figure 5.1. We hypothesize that people with high initial diabetes distress have a bigger reduction in diabetes distress than people with a low initial diabetes distress, simply because there is more room for improvement. The following hypothesis was formulated:

- **H3:** People who have higher initial diabetes distress have a larger reduction in diabetes distress than people with low initial diabetes distress

Delivering information personalized to the person with diabetes’ situation is important as shown in the interventions used to treat diabetes distress [31, 36, 55]. A personalized approach is also part of Shared Decision Making [13]. This way, tailored advice is given making the advice practical for the person with diabetes. Directly measuring personalization is hard. To our knowledge, there does not exist a measurement tool for measuring personalization. There are methods to measure certain components of personalization, for example the feeling of being heard (FBH) [65]. We hypothesize that the tips delivered via agent creates a higher feeling of being heard since it is more personalized than delivering the tips via plain text. Giving personalized information means people only get information relevant to them. This gives people the idea that someone is listening to them, which might give people a stronger feeling of being heard. The following hypothesis is formulated, also shown in Figure 5.2:

- **H4:** People using the conversational agent have a more positive feeling of being heard than the control group

5.2. Measures

In this section, we present all measures with which we measured the variables as presented in the conceptual models seen in Figure 5.1 and Figure 5.2.

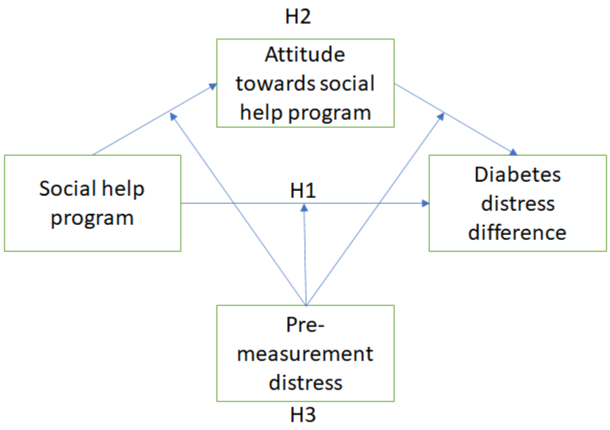


Figure 5.1: Conceptual model: hypothesized influences on the diabetes distress difference

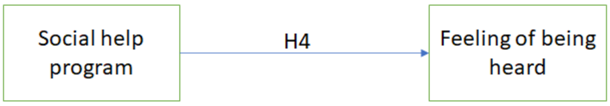


Figure 5.2: Conceptual model: hypothesized influence on the feeling of being heard

5.2.1. Determining the quality of the agent

Before testing any hypothesis, the quality of the agent should be checked. In case the quality is too low, the result of any statistical test is useless since the agent does not make any impact if the quality is too low. Therefore, the System Usability Scale is used to check whether the implementation of the conversational agent was sufficient. We consider the implementation to be sufficient if the average SUS falls at least in the “OK” category (a score of 50.9 with standard deviation of 13.8) as described by Bangor et al. [5].

5.2.2. Diabetes distress difference and pre-measurement diabetes distress

A combination of the type 1 diabetes distress scale [23] and the type 2 diabetes distress scale [52] was used to measure both the diabetes distress difference and pre-measurement diabetes distress. Specifically, we used the interpersonal distress, friend/family distress and negative social perceptions distress sub-scales from the type 1 Diabetes Distress Scale [23] and type 2 Diabetes Distress Scale [52] surveys. The questions are on a scale from 1 to 6, where a higher score means a higher distress and a lower score means lower distress. The original questionnaires contain an instruction asking to answer the questions based on what the person with diabetes has experienced in the past 4 weeks. We have changed this instruction for both pre- and post questionnaire to let the person with diabetes answer the questions based on what they expect in the coming 4 weeks. This is done because the sessions do not span an entire month and we want to have two equal measurements.

For the pre-measurement diabetes distress, we used the average score of the answers before exposure to the social help program. The diabetes distress difference was measured by subtracting the average score of the answers before exposure to the social help program from the average score of the answers after the interaction with the social help program.

5.2.3. Attitude towards social help program

The attitude towards the social help program was measured by using the Client Satisfaction Questionnaire (CSQ-8) [3]. The CSQ-8 consists of 8 items and are scored on a scale from 1 to 4. The final score is the sum of all items, giving a final score in the range of 8 to 32.

5.2.4. Measuring the feeling of being heard

The Feeling of Being Heard (FBH) [65] questionnaire was used to measure whether the type of social help the participant receives influences the feeling of being heard. The FBH questionnaire consists of 7 statements. In Tielman et al. [65], the questions were answered by using a scale where participants could indicate how much they agreed to a statement by clicking a point on a scale from “it decreased a lot”, “nothing changed” to “it increased a lot”. We have changed this to a 7-point Likert scale. Research has shown that reliability and validity of responses to questions increase when having more response options, although this increase levels off after providing 7 response options [39]. Even though a slider gives more answer options to the participant, it also makes it harder for the participant to determine which response option comes closest to their actual opinion [69]. These two findings led us to change the scale to a 7-point Likert scale. The scores are averaged to get one final score.

5.3. Procedure

The experiment included three sessions, see Figure 5.3. In the first session, participants fill in the DDS questionnaire. After filling in this questionnaire, the participant was redirected to either the text or the conversational agent. Session two only consisted of being shown the social help program and interacting with it and a set of questions asking how involved the participant is in this topic. Session three also included an interaction with the social help program. After the last interaction, the diabetes distress questionnaire was filled in again. In addition, the participants who were in the conversational agent group filled in the System Usability Scale (SUS) [5]. Participants from both groups also filled in the CSQ-8 which was used to find out whether the attitude towards the social help program is a mediator. In addition, the feeling of being heard questionnaire was filled in to measure the feeling of being heard, which is another hypothesized dependent variable. Furthermore, both groups are asked three questions measuring how involved the participant is in the topic of social diabetes distress. We have also included one attention check question in the DDS questionnaire in the first session, one attention check in the involvement questions in the second session and two attention check questions in the post questionnaires. Lastly, every session was followed by an optional open text question where participants were asked for any comments they had on the session. All questionnaires can be found in Appendix B.

A statistical power analysis was performed for sample size estimation. An effect size d of 0.5 was used, which is considered to be a medium effect using Cohen’s criteria [16]. With an error probability of .05 and power of 0.80, the projected sample size needed with this effect size is approximately 134 participants. We determined to invite 150 participants since we need roughly 134 participants to achieve the power we aim for with an approximate attrition of 10%.

We recruited English speaking adults with diabetes via the Prolific platform where people can register themselves to participate in experiments. The participants receive a small monetary payment for participation (approximately 8.40 pounds per hour). On the platform, potential participants already filled in a pre-screening questionnaire, which consists of various questions. One question is about whether the participant has diabetes. We only allowed people to participate when the participant entered ”yes” for this question. Recently, research by Jonell et al. [30] showed that using crowd workers produces results similar to participants under observation, which gave us the confidence that recruiting via this channel was reliable.

The complete procedure described in this chapter has been approved by the Human Research Ethics committee of the university under number 1130.

5.4. Analysis plan

To analyse whether or not the presented hypotheses in Section 5.1 can be supported, this section presents the statistical models and inference criteria to test these hypotheses.

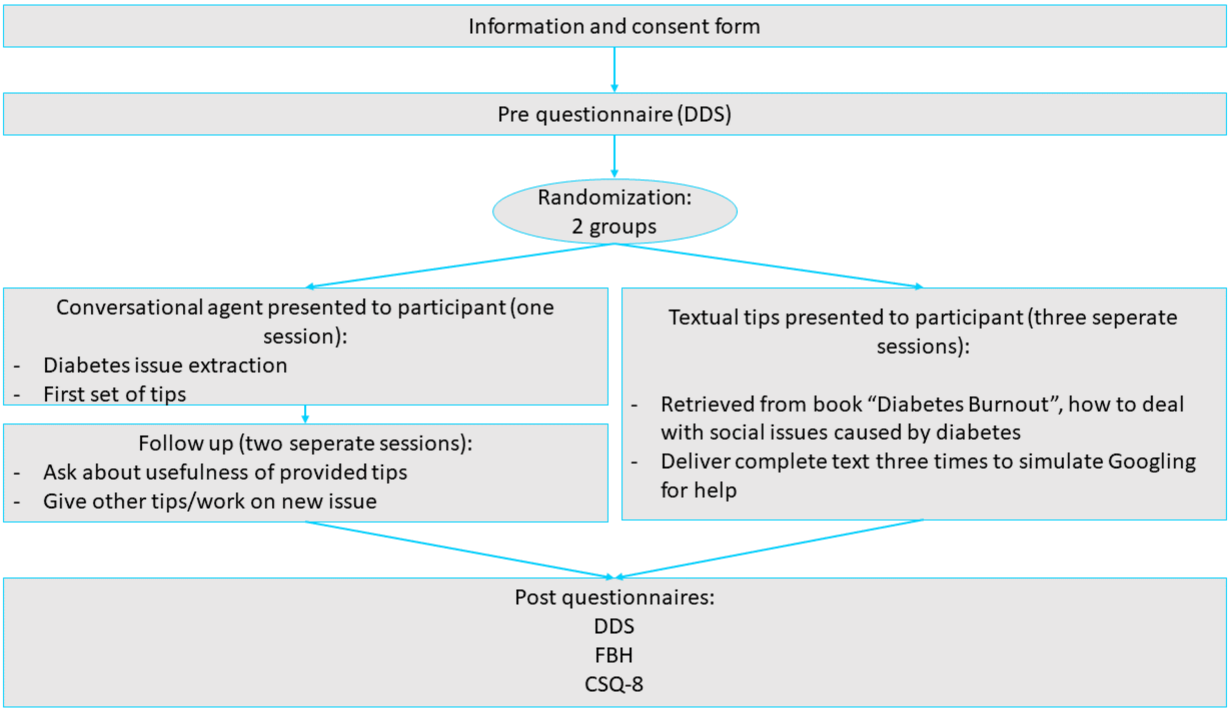


Figure 5.3: Procedure during the experiment

5.4.1. Statistical models

For testing "*People using the conversational agent have a larger reduction in diabetes distress than the control group*" (H1) and "*People using the conversational agent have a more positive feeling of being heard than the control group* (H4), a two-sided, two sample t-test was done. The dependent variable for H1 is the diabetes distress difference, the dependent variable for H2 is the feeling of being heard. For both H1 and H2, the independent variable is the social help program.

In addition, we tested "*The effect of the social help program type on the diabetes distress difference is mediated by the attitude towards the social help program*" (H2). We used the bootstrapping method of Preacher and Hayes [54] where data does not have to be normally distributed. According to Preacher and Hayes, this method addresses the power limitations of the standard Sobel test. The point estimate of the mediating effect over a 1000 random samples was computed.

To test "*People who have higher initial diabetes distress have a larger reduction in diabetes distress than people with low initial diabetes distress*" (H3), a moderation effect analysis is done by computing the interaction between pre-measurement diabetes distress and the social help program type, fitting a linear model where diabetes distress difference is explained by both variables and their interaction and checking the significance of the coefficient of the interaction term. Furthermore, we have decided not to center the independent variable and moderator since centering, with the exception of cases of extreme multicollinearity, does not make any difference for testing the interaction term [18].

When the assumptions of multiple linear regression models (such as the assumption of a linear relationship between independent and dependent variable) were not met, appropriate steps were taken.

5.4.2. Inference criteria

We used an alpha level of $p \leq .05$ for determining whether the regression analyses suggests that the results are statistically significantly different from those expected when the null hypothesis were correct.

For H2, we looked at the Average Causal Mediation Effects (ACME), the Average Direct Effects (ADE), the combined indirect and direct effects (Total Effect). The ACME here is the indirect effect of the mediator (total effect - direct effect) and thus this value shows whether the influence of the mediator is significant. A negative coefficient means that the variable causes a decrease in diabetes distress.

5.4.3. Data collection

We did not have any missing data since we used Qualtrics as a survey taking tool. Qualtrics contains validation tools on their platform which we used to validate whether the participant has answered every question. This way, partially answered questionnaires were not present. If there were still any partially answered questionnaires present, we excluded them from our analysis. We also incorporated control questions, a method to check the participants attention to the study. The first and second session both contained one control question. The last session contained two control questions because of the bigger number of items participants had to answer. If they failed any of the attention checks, their data was excluded from the analysis. Every set of participants finished the experiment within 3 weeks (first batch between November 24th - December 14th, second batch between December 7th - December 30th, last batch between January 13th - January 29th). Lastly, we replaced the Prolific ID with a random number after all data was retrieved for further anonymization.

5.4.4. Exploratory analysis

In addition to the hypotheses above, different other angles were open for exploration. Giving personalized education, showing empathy and spreading the intervention over multiple sessions were similarities we found in interventions tailored to diabetes specific issues [31, 36, 55]. We hoped to measure the personalization and empathy by using the CSQ-8 questionnaire: we hypothesized that the attitude towards the social help program is a mediator. However, we saw that the attitude towards the agent is not a mediator, possibly because the effect is already very small or because the questionnaire did not measure the construct which caused the difference between the agent group and the control group. The feeling of being heard is one of the components of personalization and might measure the underlying factors better. Therefore, we explored whether the feeling of being heard is the mediator.

6

Results

This chapter presents the results of the experiment. First, descriptive measures are reported in Section 6.1. Section 6.2 presents the internal reliability of the questionnaires used in the experiment. Then, before looking at the results for testing the hypotheses as presented in Section 5.1, the quality of the conversational agent is checked by looking at the System Usability Scale score. This is presented in Section 6.3, where the results of the hypotheses tests are also presented. Section 6.4 presents the results of exploratory research. Lastly, Section 6.5 presents a discussion about the results and gives an answer to "*Does the conversational agent provide support for people with diabetes?*" (SQ4). The code for analysis and the output can be found in the repository of the TU Delft[1].

6.1. Participants

Table 6.1 shows the features of participants in our experiment. During the first run, we noticed that there were more participants failing attention checks then expected. Additionally, the attrition in the first run of the experiment was significantly higher than expected. Both groups contained 40 participants who completed the whole experiment, meaning almost 50% of participants failed attention checks or stopped between sessions. Due to this high number of participants dropping out or failing attention checks in the first run, we increased the number of participants to 249 on Prolific to let more people enter the experiment. We ended up with 156 participants in total, meaning 38% of participants dropped out. We investigated whether there were any significant differences between the groups regarding age, gender and pre-measurement diabetes distress using a Kruskal-Wallis test, see Table 6.2. There is a significant difference ($\alpha = 0.016$) between the number of males in the control group and the number of males in the agent group. We checked whether this difference had any influence on the results. A linear model was fitted where the diabetes distress difference is explained by the gender of the participant. The gender-coefficient's p-value is 0.863, implicating that this variable does not influence the results.

Participants	Control group	Treatment group	Total
Number, n	77	79	156
–Male, n(%)	48 (62.3 %)	34 (43 %)	82 (52.6 %)
Age (years)			
–Mean (SD)	40.3 (16.3)	37 (14.9)	38.6 (15.6)
–Range	18 - 76	18 - 70	18 - 76
Pre diabetes distress			
–Mean (SD)	2.4 (1)	2.7 (1.1)	2.6 (1.1)
–Range	1 - 5.4	1 - 5.1	1 - 5.4

---

[1] https://repository.tudelft.nl/

Participants	Control group	Treatment group	Total

Table 6.1: Participants profile

statistic	parameter	p.value	variable
57.309	49	0.194	age
5.788	1	0.016	gender
43.926	42	0.390	pre-measurements diabetes distress

Table 6.2: Differences between groups on age, gender and pre-measurement diabetes distress

6.2. Internal reliability

All questionnaires are checked on their internal reliability as seen in Table 6.3. The DDS questionnaire is a combination of three diabetes distresses retrieved from the T1-DDS and the DDS, specifically the social diabetes distresses. We wanted to check whether this combination is reliable for measuring diabetes distress. The Cronbach alpha is 0.89, which is considered to be very reliable [17].

The CSQ-8 questionnaire was checked on the internal reliability for validation. With a Cronbach alpha of 0.92, reliability is high and similar to the reliability as reported by the creator of the questionnaire [3].

The feeling of being heard was measured using the FBH questionnaire. We checked the internal reliability of the questionnaire. Tielman et al. [64] reports a Cronbach alpha of 0.96 where we found a Cronbach alpha of 0.8 showing a good internal reliability [17].

The involvement questions were made by us to measure whether people are involved in the topic of social diabetes distress. Therefore, we want to see whether these questions do indeed measure the same construct. The Cronbach alpha is 0.81, showing a good internal reliability [17].

Questionnaire	**Lower CI**	**Alpha**	**Upper CI**
Diabetes Distress Scale	0.86	0.89	0.92
Client Satisfaction Questionnaire	0.89	0.92	0.94
Feeling of being heard	0.74	0.8	0.86
Involvement	0.74	0.81	0.87

Table 6.3: Internal reliability of the questionnaires

6.3. Hypotheses testing

Before testing the hypotheses, the System Usability Scale score was used to determine whether the implementation of the conversational agent was sufficient: we determined that the average SUS score should at least fall in the “OK” category (a score of 50.9 with standard deviation of 13.8) as described by Bangor et al. [5]. The mean SUS is equal to 81.6 (SD 12.0), meaning that the score is closest to either “Good” or “Excellent”, showing that the implementation was sufficient. Any assumptions for statistical models used below were tested.

H1: People using the conversational agent have a larger reduction in diabetes distress than the control group

A two-tailed Student’s t-test is done to test this hypothesis. Comparing the participants in the agent group (M = -0.305, SD = 0.865) with the participants in the control group (M = 0.002, SD = 0.743), we see that there is a statistically significant difference in reduction of diabetes distress, $t(154) = 2.377$, $p = 0.019$. For the control group, there was no reduction in diabetes distress at all while the agent group shows a reduction in diabetes distress, see Figure 6.1. The effect size for this analysis ($d = 0.38$) was found to be between a small effect ($d = 0.2$) and medium effect ($d = 0.5$) according to Cohen's convention [16].

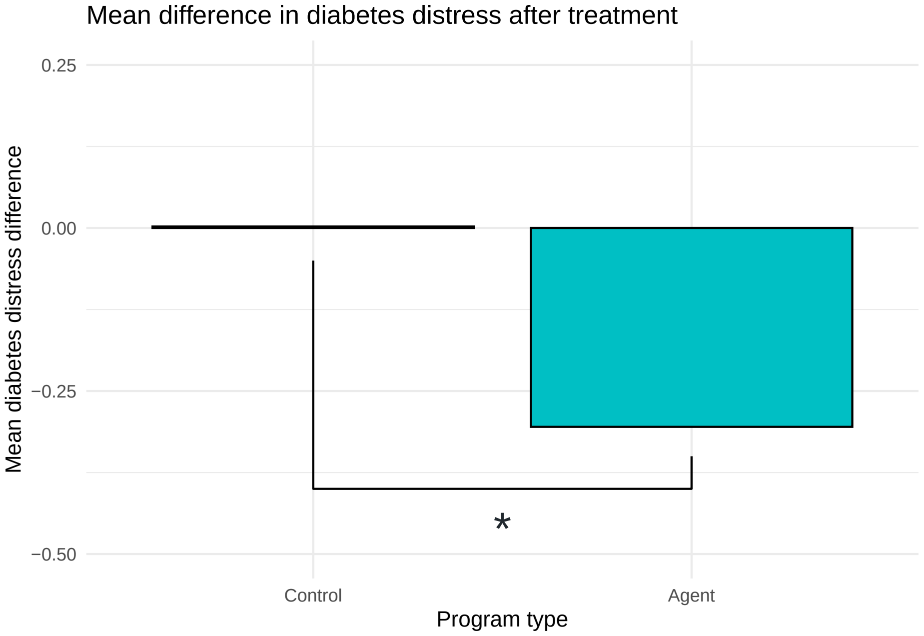


Figure 6.1: Visualization of testing H1

H2:The effect of the social help program type on the diabetes distress difference is mediated by the attitude towards the social help program

Table 6.4 shows the results of testing H2. The ACME shows the indirect effect of the social help program via the attitude towards the social help program on the diabetes distress difference. The 95% confidence interval of the coefficient of the ACME includes 0 and is not statistically significant, $p = 0.866$. The ADE shows the direct effect of the social help program on the diabetes distress difference. The 95% confidence interval of the coefficient of the ADE does not include 0 and is statistically significant, $p = 0.02$. The total effect is calculated by adding the effect of the ACME and the effect of the ADE. The 95% confidence interval of the total effect is very similar to that of the ADE as the indirect effect is negligibly small. Prop. mediated describes what part of the effect of the social help program on the diabetes distress difference is via the indirect effect. This is calculated by dividing the ACME by the total effect. The results show that this effect is again negligibly small and not statistically significant ($p = 0.866$).

	Estimate	**95% CI Lower**	**95% CI upper**	**p-value**
ACME	0.001	-0.030	0.04	0.866
ADE	-0.309	-0.586	-0.06	0.02
Total Effect	-0.307	-0.568	-0.06	0.016
Prop. Mediated	-0.004	-0.151	0.14	0.866

Table 6.4: Results H2

H3: People who have higher initial diabetes distress have a larger reduction in diabetes distress than people with low initial diabetes distress

A classic moderation analysis was done. This means we fitted a linear model where the diabetes distress difference is explained by the social help program type, the diabetes distress before exposure to treatment and the interaction between these two variables. Moderation is present when the coefficient of the interaction term is statistically significant.

Table 6.5 shows the results of fitting the linear model on the data. The coefficient of the interaction term is not statistically significant, $p = 0.075$.

	Estimate	**Std. error**	**t**	**p**
Intercept	0.502	0.226	2.222	0.028
Social help program	0.308	0.312	0.986	0.326
Pre-measurement diabetes distress	-0.205	0.086	-2.378	0.019
Social help program:pre-measurement diabetes distress	-0.202	0.113	-1.794	0.075

Table 6.5: Moderation analysis

H4: People using the conversational agent have a more positive feeling of being heard than the control group

For the feeling of being heard, a two-tailed Student's t-test is done. Comparing the participants in the agent group (M = 4.79, SD = 0.84) with the participants in the control group (M = 4.70, SD = 1.02), we see that there is no statistically significant difference in the feeling of being heard, $t(154) = -0.60$, $p = 0.55$.

6.4. Exploratory research

After hypotheses testing, we have explored another direction and created exploratory models. From the results of testing "*The effect of the social help program type on the diabetes distress difference is mediated by the attitude towards the social help program*" (H2), we see that our hypothesis is not supported. Another possible mediator is the feeling of being heard: this measures a component of personalization. Giving information personalized to the person with diabetes' situation is one of the factors we implemented in the conversational agent. Therefore, we explore whether the feeling of being heard is a mediator. The results are shown in Table 6.6. The 95% confidence interval of the coefficient of the ACME includes 0 and is not statistically significant, $p = 0.954$.

	Estimate	**95% CI Lower**	**95% CI upper**	**p-value**
ACME	-0.003	-0.028	0.03	0.954
ADE	-0.305	-0.561	-0.06	0.020
Total Effect	-0.307	-0.562	-0.06	0.024
Prop. Mediated	0.008	-0.126	0.16	0.946

Table 6.6: Results: FBH mediation analysis

6.5. Discussing the results

In this section, the results of the experiment are discussed. In addition, any limitations in the experiment are discussed and the threats to external- and internal validity are presented.

6.5.1. Answering the hypotheses

H1: People using the conversational agent have a larger reduction in diabetes distress than the control group

The results support the hypothesis: we saw that the control group shows no reduction in diabetes distress (M = 0.002, SD = 0.743) while the agent group did show a reduction in diabetes distress (M = -3.05, SD = 0.865). The effect size, $d = 0.38$, is above the threshold for a small effect ($d = 0.2$) meaning that the difference created by the social help program seems to not be trivial. This also implicates that an individualized approach of delivering advice is indeed important and corroborates other research [46, 65]. With this result, we can positively answer *“Does the conversational agent provide support for people with diabetes?”* (SQ4).

H2: The effect of the social help program type on the diabetes distress difference is mediated by the attitude towards the social help program

We aimed to explain why the agent reduces diabetes distress by using the Client Satisfaction Questionnaire. This was done by doing a mediation analysis. The results of this analysis do not support the hypothesis: we could not find that the effect of the social help program type on the diabetes distress difference is a mediating effect. Measuring personalization is hard. To our knowledge, no standardized tools available. The choice for the Client Satisfaction Questionnaire might not have been appropriate. We do see that the direct effect, the social help program, is significant.

H3: People who have higher initial diabetes distress have a larger reduction in diabetes distress than people with low initial diabetes distress

When a participant has little to zero diabetes distress, the treatment cannot make a difference. We investigated whether the diabetes distress before exposure to the treatment moderates the effect of the social help program on the diabetes distress difference. The results do not support our hypothesis as the interaction term is not significant. However, we do see that the coefficient for the pre-measurement diabetes distress is significant. This means that this variable does influence the diabetes distress difference, our dependent variable. Therefore, this pre-measurement diabetes distress is an extraneous variable. We explored what the effect is of the diabetes distress before exposure to the treatment by comparing the prediction of different linear models. This showed that the diabetes distress before exposure to the treatment does improve prediction. Since we used random sampling and saw that there were no difference in pre-measurement diabetes distress between the groups, the influence of this extraneous variable is assumed to be equal for both groups.

H4: People using the conversational agent have a more positive feeling of being heard than the control group

The results do not support our hypothesis: there is no significant difference between the feeling of being heard in the control group and the feeling of being heard in the agent group. Our approach is different than the work by Tielman et al. [65] where personalized motivational messages based on the situation (progression of PTSD symptoms and the user’s trust in a good therapy outcome) of the participant were given by the virtual agent. In our approach, the participant is given information based on the type of social diabetes distress the participant experiences. Unlike Tielman et al. we do not consider the progression of the diabetes distress and we do not consider the user’s trust in a good therapy outcome. In addition, the conversational paths are not heavily personalized: we only personalize based on the type of experienced social diabetes distress. After detecting the type of social diabetes distress, the conversation is not further personalized other then letting participants choose which tip they would like to receive. Our approach may not have been sufficient to give the participant a higher feeling of being heard than the control group.

Exploratory analysis

We have also explored whether the feeling of being heard mediates the effect of the social help program on the diabetes distress difference. We found that the results do not support our hypothesis that the feeling of being heard is a mediator.

6.5.2. Limitations

Several weaknesses of this study are in the setup of the experiment. 156 participants received a relatively short treatment of three separate sessions over a minimum period of 2 weeks. Therefore, the impact of the intervention was limited as seen by the effect size, causing a lower confidence in any conclusions drawn from the results. No follow-up was done to check whether findings still persist after some time: an intervention which does not create lasting change is not useful. The above suggests that this study should be replicated to increase confidence in the conclusions we draw here. This replication should include more sessions and a follow-up to see whether the agent is able to help over a longer time period. Lastly, the variables used in our analysis rely on self-reported measurements of the participants. This may cause responder bias, although participants in both groups would be effected by this bias in the setup we used, meaning we do not expect that this has influenced the results.

6.5.3. Validity

There may be some threats to the internal validity: 38% of participants failed attention checks or stopped in between sessions. The high number of drop-outs can be explained by the fact that we have used Qualtrics to automatically send an invitation for the next session to the Prolific email addresses of the participants, but, as some participants told us, this is not usual to do on the Prolific platform. In the future, separate Prolific studies should be created for each session: we expect this lowers the number of drop-outs. The failing attention checks can be explained by the fact that we did not include a filter where we only allow people with a certain approval rate to enter. We decided not to do this since there were 2000 eligible participants on the platform and we did not want to make this number smaller. Other crowd source platforms could be used or local hospitals could be contacted to increase this number of eligible participants. However, the high amount of drop-outs might also be explained by the fact that this intervention is too confronting, although there were no comments suggesting this. Therefore, we do not think the high number of drop-outs is a threat to the internal validity of this project.

Another threat to interval validity is the fact that we have a significant difference between the participants in both groups regarding the gender. Although we used random assignment, we ended up with more males in the control group than in the agent group. However, we have seen that the gender of the participant had no significant effect on the diabetes distress difference. Therefore, it is unlikely that this difference between groups influenced our results.

Regarding threats to external validity, no information about the type of diabetes that the participant is suffering from was available. Therefore, we do not know whether the type of diabetes may have an effect on the influence of the agent on the diabetes distress difference. Looking at the mean age and the spread, it is unlikely that the participants reflected the ratio of type 1 and type 2 diabetes in the general population: roughly 90% of all people with diabetes suffer from type 2, but type 2 is often diagnosed on later ages (45 - 64) according to the Center for Disease Control [2]. There was also no information on whether the participant is currently in therapy for diabetes distress. If many participants are in therapy, they may have received similar education before exposure to the social help program which would have influenced the results. Since the Human Research Ethics committee (HREC) of the university already advised not to include the type of diabetes of the participants, we also determined that we do not ask participants whether they are already receiving therapy. However, in future research, a clear data management plan should be created to open the discussion with the HREC about incorporating these factors.

---

[2] https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf

7

Discussion

In this chapter, a general discussion of the project is presented. First, in Section 7.1, the answers to our research questions are presented. Section 7.2 presents the limitations of this work and possible improvements on the process. In Section 7.3, the contributions are discussed. Before concluding this thesis in Section 7.5, we present some directions for future research in Section 7.4.

7.1. Answering the research questions

The aim of this project was to address the following research question:

> *Is it possible, and what is required, to use a conversational agent to help people with diabetes deal with social diabetes distresses?*

To answer this question, we created a set of sub research questions:

SQ1 *What kind of diabetes related distresses are encountered by people with diabetes?*

SQ2 *What techniques are available to help people with diabetes deal with social diabetes distresses?*

SQ3 *What are the requirements for a conversational agent supporting people with diabetes in dealing with social issues that may cause social diabetes distress?*

SQ4 *How can a conversational agent provide support for people with diabetes?*

SQ5 *Does the conversational agent provide support for people with diabetes?*

We started by answering SQ1. We found that there are different diabetes related distresses: for type 1 diabetes, we found powerlessness (feeling of no control over diabetes, fear of future complications), management distress, eating distress, hypoglycemia distress, negative social perceptions (fear of getting treated differently by others), family/friend distress and physician distress. For type 2 diabetes, we found regimen distress, emotional burden, interpersonal distress and physician stress. We compared the type 1 and type 2 distresses and found that type 1 patients experience the multiple facets of their regimen as different types of stress, while type 2 patients experience this as one type of distress. There is also a difference in hypoglycemia distress, which is only present in the type 1 diabetes distress scale. This can be explained by the fact that type 1 patients have a significantly higher chance to experience hypoglycemia than type 2 patients. With the above, we limited ourselves to the social distresses.

With the answer to SQ1, we further investigated interventions for helping people with diabetes to answer SQ2. There is a limited number of research on interventions tailored to help people with diabetes deal with diabetes distress: we found four papers reporting such interventions of which three shared some components [31, 36, 55]. These components are delivering treatment over multiple sessions, finding out the person with diabetes' individual problem and based on this problem, give tailored advice.

Moving on to SQ3, we used the answer to SQ2 and considered any ethical issues and usability to create requirements for the conversational agent. We have seven requirements, presented in Table 7.1.

R1	The agent should be able to find out what the underlying issue (diabetes distress) is when given input by the person with diabetes
R2	The agent should provide the person with diabetes with information on how to deal with social diabetes distress
R3	The information the agent will provide should be personalized to the situation of the person with diabetes
R4	The interaction between agent and person with diabetes should be spread over multiple sessions
R5	Data ownership should not be shared with external parties and data should be safely stored on a private server
R6	The conversational agent should be available in a clear, easy-to-use chat interface
R7	The conversational agent should not give advice on the use of medication

Table 7.1: Requirements for the conversational agent

A design was created with the requirements above to answer SQ4, see Figure 7.1. The components of this design were based on existing interventions [31, 36, 55] and Shared Decision Making [13]. These components are: delivering treatment over multiple sessions, determining the current status of the user, give pros and cons of strategies useful for the user's current situation and finally, based on the user's preference, give detailed information about the strategy to deal with diabetes distress.

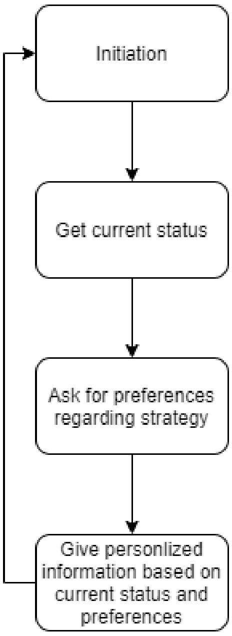


Figure 7.1: High level design of conversational agent

To evaluate the conversational agent which implements the design we created for SQ4, an experiment was done to answer SQ5. The results showed that the conversational agent created a bigger reduction in diabetes distress than the standard educational text. This implicates that an individualized approach of delivering advice is indeed important and corroborates other research [46, 65].

With the above, we return to our main research question. The evaluation of the conversational agent showed that the agent is able to reduce diabetes distress, meaning we can indeed use a conversational agent to support people with diabetes to deal with diabetes related distresses within their social environment. The findings from our first four sub-questions can be used to formulate an answer for the "*what is required*" part of our research question. We acknowledge that there is little research into interventions tailored to deal with diabetes distress. Therefore, we cannot claim that the components in the design which we created is all that is required. However, since the results in Chapter 6 show that the agent does reduce diabetes distress more than the current situation, we think that the design we created does influence the diabetes distress of the person with diabetes.

7.2. Limitations and possible improvements

We organized two focus groups. Both were with Dutch people only, and the focus group with people with diabetes and their close social environment had a very limited number of participants. To further refine our findings from focus groups, more nationalities should be included in order to correct for cultural differences, even though the focus group with health care providers did shed some light on this topic.

The design we created showed to be meaningful as the evaluation showed that the agent does make a difference. However, the design is based on a small set of existing interventions and we saw that the effect is between a small and medium effect. The design should be further refined in order to create a larger effect.

Some improvements could be made to our system. As explained in Chapter 4, Rasa advises to deploy the conversational agent as soon as possible in order to create new, fitting stories for the agent to train on and create responses. However, this was not possible in the time given for this project. Eight comments from participants indicated that the conversational agent was too limited in its conversational capabilities:

> I felt like the chatbot was leading me down a specific path and there was little point in me curating my own answers because it wasn't properly equipped to respond to them

Furthermore, the training samples created for training intent classification were all based on our own knowledge, although personal experience with diabetes is present. To improve this, the conversational data we have gathered during the experiment can be used to further improve intent classification. In addition, the system does not consider the health literacy of the participant, something which possibly impacts the influence of the agent on the diabetes distress and should be investigated in the future. For example, Wang et al. [68] investigated whether a factual or "guided" communication style was preferred for people with differing health literacies and showed that there is a difference in certain situations.

In addition, we did not look into meaningful cut-off points regarding diabetes distress. Fisher et al. [22] suggests to use three groups: low (< 2), moderate (2.0–2.9) and high (≥ 3). The meta-analysis by Schmidt et al. [58] did not include these cut-off points but used a dichotomy (low/high), where high is considered to be a DD score ≥ 3, even though the writers acknowledge that the middle group could benefit from an intervention tailored to battle diabetes distress. The influence of our agent on the diabetes distress should be investigated for each of the three groups in future research. This may lead to new requirements depending on which group the person with diabetes belongs to.

Since we do not have any labelled data for intent classification and could not ask participants to mark whether they thought the agent was correctly classifying the underlying diabetes distress, we have not looked into the accuracy of classifying the underlying diabetes distress. However, during the pilot test and the experiment, conversations were checked in order to determine whether reasonable classifications were made. An extensive analysis was not done due to limited resources. We read the conversations from the first session where the first step is to detect the underlying diabetes distress. There were situations where the participant provided an example but did not feel like their underlying problem was "too little support" or "diabetes police". This indicates that the options were too limited for certain situations. In addition, when the conversational agent detects "too little support", it asks the following:

> It sounds to me like you feel you could use a little more support, am I right?

This may be too general, since we saw some instances where we could have classified the provided example as "diabetes police". The following example provided by a participant shows such an instance:

> My problem is everyone wants to make sugar free stuff for me

The above proves that it is difficult to determine the classification accuracy of the conversational agent. In future work, a design where the conversational agent does not utter a general message as presented here would make it easier to determine classification accuracy.

Lastly, we received some comments on asking for release to the general public. For such a step, a number of issues should be addressed. The first issue is accessibility: the agent should be available 24/7, so a service like Amazon Web Services (AWS) or Google Cloud is an option, although data ownership issues should be investigated before deploying on such a service. However, we found that deploying on a TU Delft server proves to be difficult due to limited resources on the machine. Next to that, when there is maintenance on the TU Delft, all servers are done, causing the agent to become inaccessible. AWS and Google cloud have many servers which take over processes when one server is under maintenance. The second issue is the limited conversational capabilities. More response actions should be implemented to make the agent feel more “alive” and more open conversation should be made possible. This last point is also suggested by Fitzpatrick et al. [24], where qualitative analysis showed that participants wanted to have more open conversation and wanted to use less buttons. The third is to have a high classification accuracy for determining the diabetes distress, something we have already mentioned above. When these issues are fixed, more tips and diabetes distresses can be implemented. For example, Polonsky’s book [50] also contains tips on how to deal with regimen distress (or management distress for T1-DDS), so these can be implemented in the future as well.

7.3. Contributions

The first contribution of this project is that we have used literature to give a comprehensive overview of diabetes distresses, in particular social diabetes distresses. We also provided an overview of existing measurement tools to measure these distresses. This overview can be used in future research into interventions tailored to diabetes specific issues.

The second contribution is the research into requirements for a conversational agent which helps people with diabetes deal with social diabetes distresses. We have shown that there is limited research into interventions tailored to help people with diabetes deal with diabetes distress. However, the available research did share similar components.

The design we have created based on the requirements is another contribution. The agent showed to improve upon the current situation, implying that the design does help people with diabetes in dealing with diabetes distress. This design can be used as a basis for future projects in this domain.

The main contribution of this project is the evaluated conversational agent giving personalized tips for dealing with social diabetes distress. The agent was built with open source software, providing a free, reliable basis for providing education for dealing with diabetes distresses. The system could be expanded by including more diabetes distresses. In addition, a similar system as designed and implemented in this project can be used in various applications as shown in similar work [24]. The evaluation of this agent is why the agent is the main contribution: we were able to test our conversational agent with participants from our target group and showed that the agent is an improvement on the current situation.

7.4. Future research

In future research, the effect of every component of our design may be investigated in order to determine which of these components cause the effect on the diabetes distress difference. In addition, we found there was limited research into interventions tailored to help people with diabetes deal with diabetes distress. New interventions should be designed, implemented and evaluated in order to determine what works in this particular domain. Furthermore, we found no standardized measuring tools for measuring personalization and empathy. Creating these tools would be a benefit to the scientific community.

Lastly, the design we created can be further improved and used to create a similar system to also help people from the close social environment deal with their diabetes distresses.

7.5. Conclusion

In conclusion, we worked on answering the following research question:

> *Is it possible, and what is required, to use a conversational agent to help people with diabetes deal with social diabetes distresses?*

We have shown that using a conversational agent to help people with diabetes deal with social diabetes distresses is a viable option since, compared to the current situation, the agent is an improvement. An intervention like the agent implemented in this project should contain a personalized approach where information is tailored to the situation of the person with diabetes.

We are optimistic that using conversational agents such as we have implemented in this project can be an addition to the e-mental health domain. The agent we have implemented can be expanded by adding more strategies to deal with other diabetes distresses. We do recognize that more work is needed: research into interventions tailored to deal with diabetes distresses is limited. To achieve a better result, research should be done into the different factors of personalization and which of these factors cause the improvement on the current situation. In addition, standardized measurement tools for measuring these underlying factors should be developed.

With this work, we hope to lay a path for other researchers to build on, where the ultimate goal would be an intervention which helps people with diabetes get rid of diabetes distress completely. Managing blood glucose is hard enough by itself: let us aim to improve the quality of life for people with diabetes.

Bibliography

[1] Nhg-standaard diabetes mellitus type 2. `https://www.nhg.org/standaarden/volledig/nhg-standaard-diabetes-mellitus-type-2-derde-herziening`. Accessed: 6-5-2019.

[2] Irwin Altman and Dalmas A Taylor. *Social penetration: The development of interpersonal relationships.* Holt, Rinehart & Winston, 1973.

[3] C Clifford Attkisson and Thomas K Greenfield. The client satisfaction questionnaire (csq) scales and the service satisfaction scale-30 (sss-30). *Outcomes assessment in clinical practice*, 120(7), 1996.

[4] Arshiya A Baig, Amanda Benitez, Michael T Quinn, and Deborah L Burnet. Family interventions to improve diabetes outcomes for adults. *Annals of the New York Academy of Sciences*, 1353(1): 89, 2015.

[5] Aaron Bangor, Philip Kortum, and James Miller. Determining what individual sus scores mean: Adding an adjective rating scale. *Journal of usability studies*, 4(3):114–123, 2009.

[6] Elizabeth A Beverly, Rochelle G Rennie, Emily H Guseman, Alicia Rodgers, and Amber M Healy. High prevalence of diabetes distress in a university population. *The Journal of the American Osteopathic Association*, 119(9):556–568, 2019.

[7] Timothy W Bickmore. Ethical issues in using relational agents for older adults. In *AAAI Fall Symposium: Caring Machines*, pages 17–19, 2005.

[8] Timothy W Bickmore, Daniel Schulman, and Candace Sidner. Automated interventions for multiple health behaviors using conversational agents. *Patient education and counseling*, 92(2):142–148, 2013.

[9] Timothy W Bickmore, Ha Trinh, Stefan Olafsson, Teresa K O'Leary, Reza Asadi, Nathaniel M Rickles, and Ricardo Cruz. Patient and consumer safety risks when using conversational assistants for medical information: An observational study of siri, alexa, and google assistant. *Journal of medical Internet research*, 20(9):e11510, 2018.

[10] Tom Bocklisch, Joey Faulkner, Nick Pawlowski, and Alan Nichol. Rasa: Open source language understanding and dialogue management. *arXiv preprint arXiv:1712.05181*, 2017.

[11] Deborah A Butler, Jessica B Zuehlke, Alison Tovar, Lisa K Volkening, Barbara J Anderson, and Lori MB Laffel. The impact of modifiable family factors on glycemic control among youth with type 1 diabetes. *Pediatric diabetes*, 9(4pt2):373–381, 2008.

[12] Zoraida Callejas Carrión, David Griol Barres, et al. Conversational agents for mental health and wellbeing.

[13] Cathy Charles, Amiram Gafni, and Tim Whelan. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Social science & medicine*, 49 (5):651–661, 1999.

[14] Boon How Chew, Rimke C Vos, Maria-Inti Metzendorf, Rob JPM Scholten, and Guy EHM Rutten. Psychological interventions for diabetes-related distress in adults with type 2 diabetes mellitus. *Cochrane Database of Systematic Reviews*, (9), 2017.

[15] Julie Chronister, Chih-Chin Chou, and Hsin-Ya Liao. The role of stigma coping and social support in mediating the effect of societal stigma on internalized stigma, mental health recovery, and quality of life among people with serious mental illness. *Journal of Community Psychology*, 41(5):582–600, 2013.

[16] Jacob Cohen. *Statistical power analysis for the behavioral sciences*. Academic press, 2013.

[17] Jose M Cortina. What is coefficient alpha? an examination of theory and applications. *Journal of applied psychology*, 78(1):98, 1993.

[18] Dev K Dalal and Michael J Zickar. Some common myths about centering predictor variables in moderated multiple regression and polynomial regression. *Organizational Research Methods*, 15 (3):339–362, 2012.

[19] SM Dunn, HH Smartt, LJ Beeney, and JR Turtle. Measurement of emotional adjustment in diabetic patients: validity and reliability of att39. *Diabetes Care*, 9(5):480–489, 1986.

[20] Leonard E Egede and Charles Ellis. Diabetes and depression: global perspectives. *Diabetes research and clinical practice*, 87(3):302–312, 2010.

[21] Lawrence Fisher, Catherine A Chesla, Marilyn M Skaff, Joseph T Mullan, and Richard A Kanter. Depression and anxiety among partners of european-american and latino patients with type 2 diabetes. *Diabetes Care*, 25(9):1564–1570, 2002.

[22] Lawrence Fisher, Danielle M Hessler, William H Polonsky, and Joseph Mullan. When is diabetes distress clinically meaningful?: establishing cut points for the diabetes distress scale. *Diabetes care*, 35(2):259–264, 2012.

[23] Lawrence Fisher, William H Polonsky, Danielle M Hessler, Umesh Masharani, Ian Blumer, Anne L Peters, Lisa A Strycker, and Vicky Bowyer. Understanding the sources of diabetes distress in adults with type 1 diabetes. *Journal of Diabetes and its Complications*, 29(4):572–577, 2015.

[24] Kathleen Kara Fitzpatrick, Alison Darcy, and Molly Vierhile. Delivering cognitive behavior therapy to young adults with symptoms of depression and anxiety using a fully automated conversational agent (woebot): a randomized controlled trial. *JMIR mental health*, 4(2):e19, 2017.

[25] Deepak Gahlan, Rajesh Rajput, Pratibha Gehlawat, and Rajiv Gupta. Prevalence and determinants of diabetes distress in patients of diabetes mellitus in a tertiary care centre. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*, 12(3):333–336, 2018.

[26] Vicki S Helgeson, Dorothy Becker, Oscar Escobar, and Linda Siminerio. Families with children with diabetes: Implications of parent stress for parent and child health. *Journal of pediatric psychology*, 37(4):467–478, 2012.

[27] Peter Herschbach, Gabriele Duran, Sabine Waadt, Angela Zettler, Christoph Amm, Birgit Marten-Mittag, and Friedrich Strian. Psychometric properties of the questionnaire on stress in patients with diabetes—revised (qsd-r). *Health Psychology*, 16(2):171, 1997.

[28] Danielle Hessler, Lawrence Fisher, William Polonsky, and Nicole Johnson. Understanding the areas and correlates of diabetes-related distress in parents of teens with type 1 diabetes. *Journal of pediatric psychology*, 41(7):750–758, 2016.

[29] Mohammadreza Hojat, Daniel Z Louis, Fred W Markham, Richard Wender, Carol Rabinowitz, and Joseph S Gonnella. Physicians' empathy and clinical outcomes for diabetic patients. *Academic Medicine*, 86(3):359–364, 2011.

[30] Patrik Jonell, Taras Kucherenko, Ilaria Torre, and Jonas Beskow. Can we trust online crowd-workers? comparing online and offline participants in a preference test of virtual agents. In *Proceedings of the 20th ACM International Conference on Intelligent Virtual Agents*, IVA '20, New York, NY, USA, 2020. Association for Computing Machinery. ISBN 9781450375863. doi: 10.1145/3383652.3423860. URL `https://doi.org/10.1145/3383652.3423860`.

[31] Marise J Kasteleyn, Kees J Gorter, Rebecca K Stellato, Mieke Rijken, Giel Nijpels, and Guy EHM Rutten. Tailored support for type 2 diabetes patients with an acute coronary event after discharge from hospital–design and development of a randomised controlled trial. *Diabetology & metabolic syndrome*, 6(1):5, 2014.

[32] Karen M Keogh, Susan M Smith, Patricia White, Sinead McGilloway, Alan Kelly, James Gibney, and Tom O'Dowd. Psychological family intervention for poorly controlled type 2 diabetes. *The American journal of managed care*, 17(2):105–113, 2011.

[33] David A Kolb. *Experiential learning: Experience as the source of learning and development*. FT press, 2014.

[34] Katharina Kovacs Burns, Antonio Nicolucci, Richard IG Holt, Ingrid Willaing, Norbert Hermanns, Sanjay Kalra, Johan Wens, Frans Pouwer, Søren Eik Skovlund, Mark Peyrot, et al. Diabetes attitudes, wishes and needs second study (dawn2™): Cross-national benchmarking indicators for family members living with people with diabetes. *Diabetic Medicine*, 30(7):778–788, 2013.

[35] Kira Kretzschmar, Holly Tyroll, Gabriela Pavarini, Arianna Manzini, Ilina Singh, and NeurOx Young People's Advisory Group. Can your phone be your therapist? young people's ethical perspectives on the use of fully automated conversational agents (chatbots) in mental health support. *Biomedical informatics insights*, 11:1178222619829083, 2019.

[36] Femke Lamers, Catharina CM Jonkers, Hans Bosma, J André Knottnerus, and Jacques Th M van Eijk. Treating depression in diabetes patients: does a nurse-administered minimal psychological intervention affect diabetes-specific quality of life and glycaemic control? a randomized controlled trial. *Journal of advanced nursing*, 67(4):788–799, 2011.

[37] Julia Lawton, David Rankin, Jackie Elliott, Simon R Heller, Helen A Rogers, Nicole De Zoysa, Stephanie Amiel, UK Nihr Dafne Study Group, et al. Experiences, views, and support needs of family members of people with hypoglycemia unawareness: interview study. *Diabetes Care*, 37 (1):109–115, 2014.

[38] Nancy F Liu, Adam S Brown, Alexandra E Folias, Michael F Younge, Susan J Guzman, Kelly L Close, and Richard Wood. Stigma in people with type 1 or type 2 diabetes. *Clinical Diabetes*, 35 (1):27–34, 2017.

[39] Luis M Lozano, Eduardo García-Cueto, and José Muñiz. Effect of the number of response categories on the reliability and validity of rating scales. *Methodology*, 4(2):73–79, 2008.

[40] Lindsay S Mayberry and Chandra Y Osborn. Family support, medication adherence, and glycemic control among adults with type 2 diabetes. *Diabetes care*, 35(6):1239–1245, 2012.

[41] Joao Luis Zeni Montenegro, Cristiano André da Costa, and Rodrigo da Rosa Righi. Survey of conversational agents in health. *Expert Systems with Applications*, 2019.

[42] Robert R Morris, Kareem Kouddous, Rohan Kshirsagar, and Stephen M Schueller. Towards an artificially empathic conversational agent for mental health applications: system design and user perceptions. *Journal of medical Internet research*, 20(6):e10148, 2018.

[43] Brigitte Mueller, Carlos Nordt, Christoph Lauber, Peter Rueesch, Peter C Meyer, and Wulf Roessler. Social support modifies perceived stigmatization in the first years of mental illness: a longitudinal approach. *Social Science & Medicine*, 62(1):39–49, 2006.

[44] Mark A Neerincx and Jasper Lindenberg. *Situated cognitive engineering for complex task environments*. Ashgate Publishing Limited Aldershot, 2008.

[45] Jill Newby, Lisa Robins, Kay Wilhelm, Jessica Smith, Therese Fletcher, Inika Gillis, Trevor Ma, Adam Finch, Lesley Campbell, and Gavin Andrews. Web-based cognitive behavior therapy for depression in people with diabetes mellitus: a randomized controlled trial. *Journal of medical Internet research*, 19(5):e157, 2017.

[46] Bjørg Oftedal, Bjørg Karlsen, and Edvin Bru. Perceived support from healthcare practitioners among adults with type 2 diabetes. *Journal of advanced nursing*, 66(7):1500–1509, 2010.

[47] Kingshuk Pal, Charlotte Dack, Jamie Ross, Susan Michie, Carl May, Fiona Stevenson, Andrew Farmer, Lucy Yardley, Maria Barnard, and Elizabeth Murray. Digital health interventions for adults with type 2 diabetes: qualitative study of patient perspectives on diabetes self-management education and support. *Journal of medical Internet research*, 20(2):e40, 2018.

[48] Richard E Petty, Leandre R Fabrigar, and Duane T Wegener. Emotional factors in attitudes and persuasion. 2003.

[49] Matthew D Pickard, Catherine A Roster, and Yixing Chen. Revealing sensitive information in personal interviews: Is self-disclosure easier with humans or avatars and under what conditions? *Computers in Human Behavior*, 65:23–30, 2016.

[50] William Polonsky. *Diabetes burnout: What to do when you can't take it anymore*. American Diabetes Association, 1999.

[51] William H Polonsky, Barbara J Anderson, Patricia A Lohrer, Garry Welch, Alan M Jacobson, Jennifer E Aponte, and Carolyn E Schwartz. Assessment of diabetes-related distress. *Diabetes care*, 18(6):754–760, 1995.

[52] William H Polonsky, Lawrence Fisher, Jay Earles, R James Dudl, Joel Lees, Joseph Mullan, and Richard A Jackson. Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes care*, 28(3):626–631, 2005.

[53] William H Polonsky, Lawrence Fisher, Danielle Hessler, and Nicole Johnson. Emotional distress in the partners of type 1 diabetes adults: worries about hypoglycemia and other key concerns. *Diabetes technology & therapeutics*, 18(5):292–297, 2016.

[54] Kristopher J Preacher and Andrew F Hayes. Spss and sas procedures for estimating indirect effects in simple mediation models. *Behavior research methods, instruments, & computers*, 36 (4):717–731, 2004.

[55] Gwyneth Rees, Fleur O'Hare, Marian Saeed, Bronwyn Sudholz, Bonnie A Sturrock, Jing Xie, Jane Speight, and Ecosse L Lamoureux. Problem-solving therapy for adults with diabetic retinopathy and diabetes-specific distress: a pilot randomized controlled trial. *BMJ Open Diabetes Research and Care*, 5(1), 2017.

[56] Tapash Roy and Cathy E Lloyd. Epidemiology of depression and diabetes: a systematic review. *Journal of affective disorders*, 142:S8–S21, 2012.

[57] Jasmin Schabert, Jessica L Browne, Kylie Mosely, and Jane Speight. Social stigma in diabetes. *The Patient-Patient-Centered Outcomes Research*, 6(1):1–10, 2013.

[58] CB Schmidt, BJ Potter van Loon, ACM Vergouwen, FJ Snoek, and A Honig. Systematic review and meta-analysis of psychological interventions in people with diabetes and elevated diabetes-distress. *Diabetic Medicine*, 35(9):1157–1172, 2018.

[59] Daniel Schulman and Timothy Bickmore. Persuading users through counseling dialogue with a conversational agent. In *Proceedings of the 4th international conference on persuasive technology*, page 25. ACM, 2009.

[60] Amir Shevat. *Designing bots: Creating conversational experiences*. " O'Reilly Media, Inc.", 2017.

[61] FJ Snoek. De inzet van de medisch psycholoog bij de behandeling van diabetes mellitus. *Richtlijnen voor psychologische diagnostiek en begeleiding. Sectie Psychologen Algemene/Academische Ziekenhuizen (PAZ) van het Nederlands Instituut van Psychologen (NIP)*, 2004.

[62] Frank J Snoek, Nancy YA Kersch, Ebbe Eldrup, Ilana Harman-Boehm, Norbert Hermanns, Andrzej Kokoszka, David R Matthews, Brian E McGuire, Mirjana Pibernik-Okanović, Joelle Singer, et al. Monitoring of individual needs in diabetes (mind)-2: follow-up data from the cross-national diabetes attitudes, wishes, and needs (dawn) mind study. *Diabetes Care*, 35(11):2128–2132, 2012.

[63] Jackie Sturt, Kathryn Dennick, Danielle Hessler, Benjamin M Hunter, Jennifer Oliver, and Lawrence Fisher. Effective interventions for reducing diabetes distress: systematic review and meta-analysis. *International Diabetes Nursing*, 12(2):40–55, 2015.

[64] Myrthe L Tielman, Mark A Neerincx, Marieke Van Meggelen, Ingmar Franken, and Willem-Paul Brinkman. How should a virtual agent present psychoeducation? influence of verbal and textual presentation on adherence. *Technology and Health Care*, 25(6):1081–1096, 2017.

[65] Myrthe L Tielman, Mark A Neerincx, and Willem-Paul Brinkman. Design and evaluation of personalized motivational messages by a virtual agent that assists in post-traumatic stress disorder therapy. *Journal of medical Internet research*, 21(3):e9240, 2019.

[66] Myrthe L Tielman, Mark A Neerincx, Claudia Pagliari, Albert Rizzo, and Willem-Paul Brinkman. Considering patient safety in autonomous e-mental health systems–detecting risk situations and referring patients back to human care. *BMC medical informatics and decision making*, 19(1):47, 2019.

[67] Heather Wachtel and Rachel R Kelz. Developing relationships: Building patient relationships. In *Building a Clinical Practice*, pages 15–21. Springer, 2020.

[68] Wenxin Wang, Céline L van Lint, Willem-Paul Brinkman, Ton JM Rövekamp, Sandra van Dijk, Paul van der Boog, and Mark A Neerincx. Guided or factual computer support for kidney patients with different experience levels and medical health situations: preferences and usage. *Health and Technology*, 9(3):329–342, 2019.

[69] Bert Weijters, Elke Cabooter, and Niels Schillewaert. The effect of rating scale format on response styles: The number of response categories and response category labels. *International Journal of Research in Marketing*, 27(3):236–247, 2010.

[70] Garry W Welch, Alan M Jacobson, and William H Polonsky. The problem areas in diabetes scale: an evaluation of its clinical utility. *Diabetes care*, 20(5):760–766, 1997.

[71] Robin Whittemore, Gail D'Eramo Melkus, Amy Sullivan, and Margaret Grey. A nurse-coaching intervention for women with type 2 diabetes. *The Diabetes Educator*, 30(5):795–804, 2004.

[72] Robin Whittemore, Sarah Jaser, Ariana Chao, Myoungock Jang, and Margaret Grey. Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. *The Diabetes Educator*, 38(4):562–579, 2012.

[73] Robin Whittemore, Roberta Delvy, and Margaret M McCarthy. The experience of partners of adults with type 1 diabetes: an integrative review. *Current diabetes reports*, 18(4):19, 2018.

[74] WHO. Global report on diabetes. 2016.

A

Distresses for the close social environment

Defining the close social environment

Before defining which people from the social environment of a PWD belong to the close social environment, an analysis is made to see which groups of people are involved in the daily diabetes management activities.

Polonsky's book '*Diabetes Burnout*' explains some of the barriers stopping patients from properly doing their daily diabetes management activities [50]. These barriers are categorized into personal, interpersonal and environmental barriers. The interpersonal barriers can be used to determine what groups of people are involved in the treatment of diabetes:

- **Family conflict:** when there are many conflicts in the family to begin with, it is hard to commit oneself to diabetes management activities. Talking about diabetes management activities may even be a reason to fire up a new conflict between family members, so people with diabetes typically stop doing the daily diabetes management activities which has been the cause of arguments in the past.
- **Too little support:** Many patients, even those with close family members or close friends, have the feeling that they do not receive proper support [23]. An anecdote from the book shows a classic example: a patient tries to stick to a diet, but the patient's partner continues to buy a certain type of unhealthy food the patient simply cannot resist [50].
- **Too much support or the "diabetes police":** many patients also experience overly concerned people who are constantly monitoring the patient's behavior. This in turn negatively influences self-care performed by the patient. Fisher et al. [23] reports that treating the patient as overly fragile also causes distress.
- **Confusion about responsibilities:** having clear responsibilities for everyone is very important. For example, some patients report that their partner makes sure that there are enough medical supplies [40].
- **The "doormat" syndrome:** when the person who is always taking care of others is diagnosed with diabetes, it can be hard for these people to facilitate the changes needed for themselves. Polonsky shows an example where a patients cannot stop eating the cookies the rest of her family always likes to eat, but she does not want to stop buying them since she would feel like she is taking enjoyment from others [50].
- **Poor relationship with health care provider:** a major reason contributing to the poor self-care for patients is having a bad relationship with their HCP. From both Polonsky's book [50] as well as the research by Fisher et al. [23] it is clear that patients often have the feeling that the HCP

> does not really understand the needs of the patient and does not understand what it is to live with diabetes. Next to that, they feel that their HCP does not provide enough education and that the HCP accuses the patient of not making an effort.

From the above, it is clear that family members, partners, close friends and the HCPs have an influence on the daily diabetes management activities. This is also evident from other sources: Mayberry et al. [40] used focus groups and questionnaires to find out whether there are relations between diabetes specific supportive behavior and medical adherence. The results show that a family showing diabetes specific supportive behavior increases the patient's medical adherence. Vice versa, a family showing negative behavior results in a decrease in medical adherence. Keogh et al. [32] showed that involving one close family member or close friend in an intervention for poorly controlled diabetes patients led to better blood sugar level control, perception of support and improved diabetes management activities. During this intervention, the PWD took a close family member or friend to a set of meetings with the HCP.

The influence of HCPs on the day-to-day management of diabetes has been investigated by Oftedal et al. [46]. This research reports that patients perceive HCPs to be supportive when they show empathy, give practical advice and information, involve the patient in decision making, giving more individualized information and giving the option to share with peers. The paper suggests using motivational interviewing, a technique also used in research with conversational agents [65]. In another research, HCP empathy is shown to be positively correlated with better average blood glucose levels [29].

Next to the interpersonal barriers which stop people with diabetes from doing their daily diabetes management activities, the personal and environmental barriers also show that some people with diabetes stop doing diabetes-related self-management activities when in public. This may cause serious inconvenience for the PWD, see the quote below about blood glucose monitoring [50]:

> If you are out in public and you want to check your blood sugar in private, you have to find a place to do so. This may not be easy. The perfect image of inconvenience may be sitting in a bathroom stall while precariously balancing and using your monitoring equipment.

This need to monitor blood glucose levels in private is related to the social stigma people with diabetes often encounter as described by Schabert et al. [57]. The research also describes that this stigma is most often experienced when people with diabetes are doing one of the daily diabetes management activities such as monitoring blood glucose levels, injecting insulin, taking medication and watching their diet. These activities are visible to others and thus may draw a negative reaction from the social environment. These negative reactions often carry messages of blame ("you could have been healthy if you did not eat all those snacks"), fear or disgust. To show how social stigma influences people with diabetes, two examples are given. Some people with diabetes refuse to manage their diabetes when they are at work because of fear that employers or colleagues start to see them as ill or weak, or even as drug users when a PWD is insulin dependent. Sometimes people with diabetes also stop managing their diabetes when among friends or family, since monitoring blood glucose levels is an excellent opportunity for the social environment to comment on the health of the PWD.

From the above, it is clear that many people are involved in the day-to-day management of diabetes, some in a lesser extent than others. Family members, partners, close friends, casual friends, colleagues, employers, HCPs and strangers, all have some form of influence on a PWD. However, family members, partners, close friends and HCPs have the most influence on a PWD as these groups are involved the most in the daily management as evident from above. This can also be derived from the social penetration theory (SPT) [2]. This theory is known for its 'onion' analogy: the more information people have about each other, the deeper the relation will be. The nature of this information swapping is reciprocal, which may explain why these groups of people also experience diabetes distress. SPT distinguishes five stages in a relationship: the orientation stage, the exploratory affective stage, the affective stage, the stable stage and optionally the de-penetration stage. A relationship in the orientation stage and the exploratory affective stage is typically a casual friendship and most relations do not progress any further than this stage. The people with the most influence have relationships with the PWD in the affective stage or stable stage.

The above leads to the definition of the CSE of a PWD: it consists of family members, partners and close friends. Although HCPs have a lot of influence, the relationship is professional. Thus, they are not considered part of the CSE.

Distresses for CSE

Diabetes also affects the people around a PWD. Diabetes communities and organizations such as The Global Diabetes Community[1], the Diabetes Fonds[2] and Stichting Kinderdiabetes[3] have shown that it has a great impact on the whole family. These social organizations report that, after diagnosis, the family sometimes shows signs of going through the stages of grief. Next to that, close friends and family members worry about the long term: what will happen with the patient since there are so many potential complications he or she can suffer from? This uncertainty makes it stressful for the close social environment as well. The impact of having a relative with diabetes has also been investigated in the Diabetes Attitudes, Wishes and Needs 2 (DAWN2) study [34]. From the 2057 interviewed family members, 44.6% indicate that it has an effect on emotional well-being. 61.3% of the participants answered that they experience a lot of stress because they worry about the patient having a hypo.

To detect the different causes of diabetes-related distress in the CSE of a PWD, similar instruments were developed like the T1DDS and DDS surveys. One of these instruments is the Parent-DDS scale. This scale is a result from a research by Hessler et al. [28]. This research focused on parents of teens with type 1 diabetes since previous research showed that parents experiencing a lot of stress often results in the child having worse average blood glucose levels (and vice versa) [11, 26, 72]. The resulting Parent-DDS survey is a 20-item long questionnaire covering parent/teen relationship distress, personal distress, teen diabetes management distress and health care team distress.

Next to the Parent-DDS, there is also an instrument to see whether partners of people with diabetes are experiencing diabetes distress, which is called the Partner-DDS scale [53]. This survey consists of 22 questions covering partner diabetes management distress, how best to help distress, diabetes and me distress and hypoglycemia distress. The research behind this survey is focused on type 1 diabetes. However, the research does mention that partners of type 2 patients may also experience distress, sometimes even more than the PWD and particularly when the partner is female [21].

As with T1DDS and DDS, Parent-DDS and Partner-DDS share multiple questions. Some of these questions are categorized into different distresses. However, the main differences are in the how best to help distress and the health care team distress: how best to help distress is not listed in the Parent-DDS while the health care team distress is not included into the Partner-DDS.

Strategies for the close social environment

Even though there are some instruments available to detect diabetes distress (see above) in people from the CSE of a PWD, there is still little support given by HCPs to this group [53]. Lawton et al. [37] shows that the people from the CSE of a PWD are “in the shadow of the patient” and concludes that raising awareness of this problem among HCPs is essential to help this group deal with diabetes distress.

That there is work to be done in this field is supported by Whittemore et al. [73]. The study shows that people from the CSE of a PWD express that they receive little education, lack certain skills and receive little support on how to manage hypoglycemia. The study also shows that more research is needed to find out optimal intervention methods, delivery of such an intervention and understanding unique needs for different types of needs.

Some work has been done in involving family members more into the usual care. In these researches two strategies are being used, which are education and involving people from the CSE more. In research by Keogh et al. [32], people with diabetes and one person from their CSE received three weekly sessions by someone who had experience in using motivational interviewing. The research also stresses that educating someone from the close social environment can have a positive effect on

---

[1] `https://www.diabetes.co.uk`

[2] `https://www.diabetesfonds.nl/`

[3] `https://stichtingkinderdiabetes.nl`

the patient's treatment adherence. However, education should not just be focused on diabetes itself, but also diabetes care and the personal side of it. This helps to increase the social environment's empathy and involvement as well as knowledge, making people prone to provide support more often [50]. A review by Baig et al. [4] shows that most interventions are mainly focused on involving people close to the PWD into the usual care and are focused on educating these people on how to deal with diabetes-related stress or diabetes care. However, none of these interventions have a primary focus on diabetes distress in people from the CSE.

B

Questionnaires used for analysis

Diabetes distress

The information shown below is retrieved from work by Fisher et al. [23] and Polonsky et al. [52].

Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 11 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 11 items you think will bother you in the coming 4 weeks and tick the appropriate box.

Please not that we are asking you to indicate the degree to which each item you think will bother you in your life, NOT whether the item is merely true for you. If you feel that a particular item will not bother you or be a problem for you, you would tick the first box ”not a problem”. If it will be very bothersome, you might tick the last box ”A very serious problem”.

Question	**Distress**
Feeling that your friends and family are not supportive enough of your diabetes management efforts?	Interpersonal distress
Feeling that friends or family don’t appreciate how difficult living with diabetes can be	Interpersonal distress
Feeling that friends or family don’t give me the emotional support that I would like	Interpersonal distress
Feeling that my family and friends make a bigger deal out of diabetes than they should	Friend/family distress
Feeling that my friends and family worry more about hypoglycemia than I want them to	Friend/family distress
Feeling that my friends or family treat me as if I were more fragile or sicker than I really am	Friend/family distress
Feeling that my friends or family act like “diabetes police” (bother me too much)	Friend/family distress
Feeling that people treat me differently when they find out I have diabetes	Negative social perceptions
Feeling like I have to hide my diabetes from other people	Negative social perceptions
Feeling that people will think less of me if they knew I had diabetes	Negative social perceptions
Feeling concerned that diabetes may make me less attractive to employers	Negative social perceptions

Scale: from 1-6: not a problem, slight problem, moderate problem, somewhat serious problem, serious problem, very serious problem

Client satisfactions questionnaire

The information below is retrieved from Attkisson et al. [3].

We are interested in how you would rate the information provided to you. Please consider the following statements about the services we have given you.

How would you rate the quality of the services you have received?	Poor	Fair or moderate	Good	Excellent
Did you get the kind of service you wanted?	No, definitely not	No, not really	Yes, generally	Yes, definitely
To what extent has our program met your needs?	None of my needs have been met	Only a few of my needs have been met	Most of my needs have been met	Almost all of my needs have been met
If a friend were in need of similar help, would you recommend our program to him or her?	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
How satisfied are you with the amount of help you have received?	Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied
Has the service you received helped you to deal more effectively with problems/difficulties?	No, it seemed to make things worse	No, it really didn't help	Yes, it helped somewhat	Yes, it helped a great deal
In an overall general sense, how satisfied are you with the services you have received?	Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied
If you were to seek help again, would you come back to our program?	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

Feeling of being heard

The information below is retrieved from Tielman et al. [65].

Consider the following statements. Please think about how the services provided to you made you feel.

The social help program really addressed your needs
The social help program made you feel like you were being taken seriously
You're satisfied with the (emotional) support you received from the social help program
The social help program was appropriate to you
The social help program made you feel like attention was payed to you
The social help program made you feel like your preferences were taken into consideration
The social help program made you feel like someone only thought about what is best for you

Scale: from 1-7: strongly disagree, disagree, slightly disagree, neutral, slightly agree, agree, strongly agree.

System usability scale

Please select the appropriate answer.

I think that I would like to use this system frequently
I found the system unnecessarily complex
I thought the system was easy to use
I think that I would need the support of a technical person to be able to use this system
I found the various functions in this system were well integrated
I thought there was too much inconsistency in this system
I would imagine that most people would learn to use this system very quickly
I found the system very cumbersome to use
I felt very confident using the system
I needed to learn a lot of things before I could get going with this system

Scale: from 1-5: strongly disagree, disagree, neutral, agree, strongly agree.

Involvement

We are interested in how involved you are in the topic of socially related diabetes distress. Please consider the following statements.

I find the topic of socially related diabetes distress interesting
I find the topic of socially related diabetes distress involving
I find the topic of socially related diabetes distress personally relevant

Scale: from 1-7: strongly disagree, disagree, slightly disagree, neutral, slightly agree, agree, strongly agree.