

Description Peter scenario

Shared decision making phase diabetes type 1

Before consultation

Peter wants to visit his internist for his quarterly checkup at the hospital. He has been diagnosed with Type 1 DM since he was 19 years. Thus for 24 years he has been living with Type 1 DM. Quite a long time. Peter and his internist make an appointment. Before this appointment Peter is scheduled for some lab research and is invited to fill out some online questionnaires in the online patient portal.

Consultation

Consent to use POWER2DM

Prior to starting the consultation, a specialized diabetes nurse asks Peter if he would like to use a new system 'POWER2DM' that supports people with diabetes taking care of themselves. The specialized diabetes nurse asks consent at the beginning of the consultation, because the internist wants to use POWER2DM immediately during the consult. The specialized diabetes nurse provides more explanation regarding the kind of support POWER2DM provides, like providing different reminders, counselling to improve management of the disease, and forecasting how glucose levels develop depending on insulin/medication, food and exercise. It is a digital system using a webservice and a smartphone application. Peter is immediately charmed by the idea. Peter always carries his smartphone, and has a tablet, a laptop from his work and a desktop at home. So this new system really fits well in his daily digital routines.

Peter signs the Patient Consent Form and the specialized diabetes nurse creates a new account for Peter. The specialized diabetes nurse reminds Peter that the consent also implies that Peter's clinical information, lab and questionnaire results are entered into the POWER2DM account. This could be done automatically in selected centers, or by uploading information by a POWER2DM member in other centers, depending on availability and legislation in the different clinical settings. Because Peter will take part in the pilot study of Power2DM, the consent also applies that his data will be used for research purposes. The nurse explains that this means that the data of Peter will be stored anonymously into the research database, and that researchers will not be able to relate data to Peter, but that data of all research patients will be used to indicate effects at a group level. The nurse explains that for Peter, this means that he will be requested to share his data for project purposes under specific rules.

Anamnesis (WHERE? & WHAT?)

Lab and questionnaire results are available in the consult.

Peter's HbA1c (= 56 mmol/mol) and BMI (24) are fine. However, after his internist inquires how Peter is doing, Peter admits that managing his T1DM is getting more and more a burden. He would like to have a normal life, and monitoring his glucose levels and injecting insulin are continuously reminding him that his life is not normal. Therefore, Peter doesn't follow his care regimen as exactly as he used to. As a consequence, he is more frequently hindered by hypers and hypos, which interfere with important aspects of his life, like his work and relationship. In addition Peter feels guilty that he is not strictly following his T1DM regimen. Overall, he is quite sad how his life is going on the last months. The internist and Peter conclude that there is a problem because Peter views his diabetes regimen as a

burden and as a result, he is not sufficiently monitoring his glucose levels and not properly taking his insulin/medication. The internist registers the results of the anamnesis into POWER2DM.

Identification (WHY?)

Peter's main problem is his negative feelings/attitude regarding his T1DM care plan. He is tired of managing his disease and the prospect of always having to take care and never to let go. He feels overwhelmed and stressed by the idea. There is a specific psychological barrier, although Peter is an intelligent and highly educated person and has been dealing with his T1DM for 24 years. So he knows what to do and has the skills to do it, but is overwhelmed at the prospect of life-long care for a chronic condition at the moment. This realization of his life-long burden prohibits him to engage in healthy behavior, although he wants to be healthy. His care plan is a constant reminder of his illness. However, it seems that the burden of his care plan is two-sided. First, it interferes with his daily life because he has to monitor too often. Second, it is a cognitive burden, because he should not forget to monitor. There are no problems related to the broader socio-demographic topics, like social support, employment or family issues. The Internist registers problem identification into POWER2DM.

Shared decision making about treatment goals

Peter and his internist discuss his negative feelings towards his T1DM care regimen. Peter tells that he is really tired of taking care of his disease. His internist points out that Peter says he wants a normal life, but by not monitoring his glucose levels he is actually bringing about an abnormal life cause of the resulting hypes and hypos. Peter acknowledges this contradiction, but says he still feels abnormal because of the continuous monitoring. The internist refers Peter to the medical psychologist of the diabetes team to further discuss his sad feelings about the continuous burden of T2DM. The internist and Peter do agree on the ultimate goal to reduce the burden of hyper- and hypoglycaemia in his life by adjusting his glucose monitoring and insulin injects so that it better fits his daily life, and on the long term goals making blood glucose monitoring a habit before sports, meetings and family events within the next 3 months and carrying quick carbs daily. They hope this will result in less hindrance of hypes and hypos in sports, work, family and social activities. With the help of MT2D-MARVEL and Risk engines, POWER2DM facilitates the goal setting process; it shows the contradiction between the current and planned situation and the long-term benefits for Peter of the plans made. The internist puts ultimate + mid- + long-term goals into POWER2DM.

Shared decision making about treatment plans

Peter and his internist decide that for diminishing the negative effects of hypos Peter should carry quick carbs all the time, so he can take them when a hypo starts. Peter will decide at home which quick carbs suits him best. Peter is an experienced diabetes patient and recognizes the start of a hypo pretty correctly, but POWER2DM may provide additional warnings. KADIS enables the prediction of a hypo and a warning can be sent to Peter's smartphone at the time when the glucose level is predicted as being too low. In order to reduce the extent of monitoring and also the reminder of his disease, they decide that monitoring glucose levels is especially important before sports, meetings with friends and family events. They decide that Peter allows POWER2DM to connect to his digital agenda so reminders can be sent to his smartphone before social and sport meetings. He

will be reminded of preparing and bringing a bag with monitoring equipment to these events (Behavior Change Techniques = BCT: prompt specific goal setting and action planning). In order to form habits, POWER2DM will send Peter a compliment on his smartphone when he completes a check (BCT: Provide contingent rewards).

Peter and the internist agree upon short-term goals (i.e., reduce (specific/general) psychological barriers; WHY?) with committed action plans to reach the mid-/long-term goals.

Internist registers short-term goals + committed action plans into POWER2DM

Internist registers that POWER2DM should warn Peter when glucose levels exceed XXX.

(OPTIONAL) If KADIS is recommended, specify action plan (introduction and education regarding KADIS, instructions for baseline data collection phase; CGM usage, logging calorie intakes, physical activities, Metabolic Fingerprint, etc) for baseline data collection.

Summary Treatment Goals and Plans

Ultimate goal: reduce the burden of hyper- and hypoglycaemia in his life by adjusting his glucose monitoring + by adjusting insulin injections so that it fits his daily life

Mid-/long-term goal: within the next 3 months making blood glucose monitoring a habit before important daily life + improve insulin injections

Short-term goal: within the next month, monitor blood glucose measurements before going to sports, meetings with his friends from the university and family events + carrying quick carbs daily.

Barrier: feeling sad, forgetting to monitor his glucose level in case of meetings with friends from the university

Action plans:

1. send warnings at specific time that KADIS predicts too low glucose level
2. set reminder in smartphone before social and sport meeting through digital agenda
3. decide which carbs suits him best to carry daily
4. preparing a bag with monitoring equipment + quick carbs
5. bringing monitoring bag to sports, meetings with friends and family events.

