Do People with Diabetes Follow the Recommendations? A Study of Motivational and Compliance Factors of People with Type 1 Diabetes

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Abstract. The number of people with diabetes is increasing and today more than 8.5% of the adult population is diagnosed with diabetes. People with diabetes must make significant changes to their life and habits and adjust it to the recommendations for diabetic treatment to avoid or delay complications related to the illness. In this paper, we present empirical data from a survey, experience sampling data and interviews that addresses people with type 1 diabetes' adherence with the recommended blood sugar measurements, their physical activity level and motivational factors. This information is used to understand and explain people with diabetes' adherence to follow the recommendations using theories about self-efficacy and motivation. Finally, we give recommendations for how digital solutions can be designed that can aid the users and motivate them to follow the recommendations and hereby potentially improve the quality of life for diabetes patients.

Keywords: Motivation · Diabetes · Persuasive technologies · Experience sampling method

1 Introduction

Diabetes is a disease where the body does not produce or use insulin very well. Insulin is a hormone used to help your body absorb glucose and turn it into energy. If the glucose is not absorbed it will stay in the blood which over time can cause severe health problems [1]. Type 1 diabetes mellitus is an autoimmune chronic disease where the pancreas does not produce insulin. As a result, people with type 1 diabetes must inject insulin themselves. The amount of insulin varies depending on food intake and activity level. People with diabetes must measure the blood sugar level daily to ensure the right level of insulin [1]. When physical active, people with diabetes need to know how the activity affect the blood sugar why health professionals recommend that the blood sugar is measured before, during and after the activity to adjust the insulin level [1]. Reports from healthcare professionals at Aalborg University Hospital South [13] and a qualitative

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survey (n = 138) conducted in 2018 [14] give the impression that people with diabetes rarely do the recommended blood sugar measurements.

In this paper, we present empirical data from surveys and interviews that addresses people with type 1 diabetes' adherence with the recommended blood sugar measurements and physical activities. To understand and explain people with diabetes' adherence to follow the recommendations we use a theoretical framework comprised of: Banduras' Self-efficacy [2], Decis' and Ryans' Extrinsic motivation [3]. Finally, we give recommendations for how digital solutions can be designed that can aid the users and motivate them to become more active and do the blood sugar measurements more regularly and hereby improve the quality of life for people with diabetes.

2 Background

The number of people with diabetes have increased from 108 million globally in 1980 to 422 million in 2014. This correspond to an increase in prevalence for adults over 18 from 4.7% (1980) to 8.5% in 2014 [6].

Diabetes can cause blindness, kidney failure, heart attacks, stroke and lower limb amputation; however, people with diabetes can delay or avoid the complications with the right diet, physical activity and the correct use of medication (insulin) [7]. People with diabetes must make significant changes to their life and habits and adjust it to the recommendations for diabetic treatment e.g. change their diet, activity level and monitor the blood glucose level daily [8]. Making behavioral changes and maintaining the new habits require the patient to have a high degree of health literacy which is defined by WHO as: *"The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health"* [12].

In the specific case of diabetes - health literacy can be translated into people with diabetes' motivation to do blood sugar measurements, understand the measurements and use the information to adjust the amount of insulin along with other things such as how their activity level and food intake/type affect their health. Here we apply Deci and Ryan's definition of motivation who describes motivation as "*to be moved* to do something" [15]. Such motivation is linked with the feeling of wanting and doing something which leads to the question of why they are doing it? In the process of working with motivation, Deci & Ryan developed the 'Self- Determination theory' (SDT). SDT distinguishes between different types of motivation based on different reasons or goals that causes an action. *Intrinsic motivation* refers to doing something because one enjoys it or finds it interesting, such there are no expectation of a reward nor punishment, and *Extrinsic motivation* refers to doing something because it leads to a seconded outcome such focus is goal or reward oriented [3]. Not everyone possess the same level of intrinsic motivation because individuals are attracted to various things and subjects. Therefore Deci and Ryan focuses on humans native psychological needs for competence, autonomy, and relatedness as factors that, when fulfilled at the same time, enhances intrinsic motivation [15]. SDT takes the approach that external goals has a negative impact on an individuals' intrinsic motivation hence focus changes from wanting to do something into gaining a reward. If an individual is presented with a free choice of work, feels competent in doing so and experience cohesion Intrinsic motivation becomes stronger in the individual.

The feeling of competence is highly related to Self-efficacy defined by Bandura as *"… people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives"* Self-efficacy beliefs determine how people feel, think, motivate themselves and behave [16].

A strong sense of efficacy enhances humans' well- being in many ways. Individuals with a high sense of efficacy approaches difficult task as a challenge to be mastered, rather than threats to avoid. When experiencing failure these individuals quickly recover, attributing the failure to insufficient effort, or lack of skills which are acquirable. Such an efficacious outlook fosters intrinsic interest and deep fascination in activities and pursuing personal goals. Individuals with a reduced sense of efficacy, avoid difficult tasks, which they think of as personal threats. When confronted with a difficult situation or task, they focus more on their lack of skills or the possible bad outcomes, rather than focusing on how to solve the task or situation successfully. To change the behavior of people with diabetes we therefore must understand what motivate people with diabetes to take the necessary actions and ensure that they can do so while maintaining a high level of self-efficacy. Knowing the motivational factors is the first steps in designing a digital tool that can aid the users and motivate them to follow the recommendations. Digital solutions with the purpose of motivating people to behavioral changes are known as persuasive technologies.

Persuasive technologies and design have increasingly been used within the area of health [9]. Captology is the study of Persuasive Technology and focuses specific on how people can be motivated or change attitude by interacting with technical products. J B Fogg has been doing research in Persuasive technology since the 90's and believes that the commissioning for behavior change depends on three variables (1) Motivation (2) Ability (3) Triggers. These three variables are dependent of each other and therefore needs to be activated simultaneously, which is why Fogg developed the equation B = MAT. Fogg believes that triggers should be recommending instead of instructional hence a behavior change is focused around the individuals own choice and intrinsic motivation [17].

One commonly strategy when using PT is tailoring the persuasive communication between the user and the system [18]. Tory Higgins developed two main motivational strategies when using PT. Promotion- Orientation which is a strategy that is focused on accomplishments and potential gains and Prevention-Orientation which is focused on safety, security and preventing potential losses [18]. Conducted a study on how individuals, who wanted to change behavior, perceived tailored health messages using Higgins' strategies. For the test they developed three types of messages one was promotion-oriented which highlighted the benefits of being physical active, and two was within the frame of prevention-orientation. Type 1 stressed the risks and consequences of not engaging in regular activity, and type 2 highlighted those health risks that can be avoided by performing regular activity. Their findings indicated that Promotion-messages are perceived to be the most effective, the second most persuasive message was Prevention-message type 1 and the least effective, prevention message type 2. They also did find a correlation between the level of motivation and the perceived persuasion from the messages.

Today continuous glucose monitoring solutions exists where blood glucose meters measure the glucose level in real time and insulin pumps can be adjusted to give the right amount of insulin [10]. According to the researchers, the information about how patients should use the data from the system in everyday life situations are lacking. This may lead to inefficient use and undesirable fluctuations in the blood glucose. Another shortcoming of the systems is that they are relatively big and hence not suitable to wear while doing physical activities. Only recently have the first activity trackers for diabetes started to emerge [11]. Activity trackers can potentially be useful for people with diabetes, but researchers report on several issues that prevent the optimal use of the information provided by the devices. Lack of access to the raw data, delays, synchronization problems and the devices overheating is among the reported problems. The preliminary results show potential for wearable solutions but how these systems can be utilized to support the patients and improve the treatment is relatively unexplored [10, 11].

3 Data Collection

The data collection methods consisted of a survey, an experience sampling survey and two qualitative interviews. The different methods and purposes will be presented in the following section.

3.1 Surveys

For data gathering, an electronic survey (survey 1) with a combination of qualitative and quantitative answering options were designed. Thus, investigating the people with diabetes' current behavior for adherence with their diabetes when being psychically active.

The survey was sent by email to a group of respondents (n = 105) whom the researchers had contacted in the early phase of the project. The survey was active for a period of two weeks, which resulted in 23 valid responses.

3.2 Experience Sampling

To compare respondents' responses of their experienced behavior with their actual behavior, we designed an electronic survey within the frame of Experienced Sampling Method (ESM survey). This is a diary-based method that allows researchers to explore the nature and quality of the respondents' experienced situation here and now [19]. A quantitative electronic survey, with the possibility of elaborating answers, containing six questions, was prepared. This was emailed once daily to the 23 respondents responding to the first survey. The emails were sent at varying times over a three-week period, with a total of 11 respondents contributing throughout the period.

3.3 Interview

Two qualitative unstructured interviews with two adult people with diabetes were conducted, such validating their preferred type of messaging when using PT. We had in advance designed 5 different types of messages within the frames of Promotion and Prevention-orientation and asked the people with diabetes to validate their preferences.

3.4 Analysis

Launsø et al's scheme [21] were used to classify data, which is a further development of Kvales' condensation method. Data was analyzed according to the principles of Grounded theory steps 1–3 [20]. 1) The analysis process was initiated by open coding, which creates an overview of data, thereby initiating a preliminary contextual classification. 2) The process continued with axial coding, where clarification of contexts was systematized in to main and subcategories 3) the process then continued with selective coding where we attempted a clarifying of contexts between the general categories, allowing us to focus on the contexts in a more abstract manner.

The quantitative data from survey 1 and the ESM survey where calculated and presented as percentage. A minor error occurred for some of the subjects answering the question in survey 1: 'have you been physically active today' two respondents experienced technical problems with the survey, when trying to answer NO. They have thus answered YES to the question and later elaborated in the open section of the survey that the reality was different. For example one wrote "I have answered yes, but my bicycle-tire ruptured, so I had to take the bus, I could not choose NO so I write here instead" As the researcher wanted data regarding activity level for a better understanding of the respondents behavior, these responses were adjusted from YES to NO according to the respondents statements, and the answers from the YES section regarding motivation etc. deleted.

4 Results and Analysis

4.1 Respondents

The respondents of this investigation were a heterogeneous group belonging to the upper- and middle-class society with education levels of a minimum 2-year higher education or longer. All respondents had Diabetes mellitus type 1 with various levels of duration and type of tools for diabetes care. 91% of the respondents from survey 1 informs that they are being physical active. The information about the subject is inconsistent when reading answers from survey 1 and the ESM survey where 79.2% of respondents informs that they are physical active in the 3-week period. The respondents expressed reasons as illness and problems with a deviating blood sugar as results of inactivity during the 3 weeks.

4.2 Registration and Measuring Blood Sugar Levels During Physical Activity

In general, the respondents express that they comply with the recommendations regarding registration of blood sugar, which is recommended for 4 times daily. Thus, consensus is identified in data from survey 1 and the ESM survey where measurement at least 4 times a day is stated to be 76% and 84%.

82% of the respondents inform that they do not register blood sugar levels during physical activity. They explain reasons for this as, them being disturbed in the activity they are performing because of the timeframe for measuring and registration of blood sugar, which they experience as being too long. They tend to forget measuring and

registration, because their focus is on the activity and not the diabetes care, some do not feel the need to perform the measurements and registrations, and some express a need to avoid other peoples' awareness such thoughts about stigmatizing have emerged. Results from the preliminary survey from 2018, showed that people with diabetes felt stigmatized, and would prefer to use a smartphone or other fitness tool, for their diabetes care it would minimize the experience of stigma [13]. Of the 9% who measured and registered blood sugar both before, during and after physical activity, the percentages vary depending on the level of physical activity. Such the percentages are represented at High activity level = 18% moderate activity level = 36% and Low activity level = 9%.

72% of the respondents does not use a digital fitness tracker, like a watch or a bracelet, this is because of varies reasons like them experiencing that they have enough digital tools to attend to, they are not motivated by it, or it is too expensive. 46% of the 72% would use a fitness tracker if they had the possibility of measure and register blood sugar levels with it.

4.3 Motivation

The respondents' information about physical activity was distributed within Deci and Ryan's taxonomy. Some respondents felt externally regulated because of health specialists expecting physical activity as part of their adherence. The diabetic, in consultation with the hospital and own doctor, formulates goals for blood sugar levels, which should be adhered to in order to obtain a good self- management of the disease. The degree of motivation is thus identified as Adopted regulation.

The level of Integrated regulation are also identified by the respondents' indications of them being physically active, because they think that it is good for their health this being expressed of men 45% and woman = 36%. Intrinsic motivation is indicated by a higher percentage in men = a total of 63% versus 27% in women.

Of the qualitative data it is shown that woman are often physical active in a social setting together with people from their family or close friends. They also express intrinsic motivation for task they like to do in the household such being physical active at a low level. For example, polishing windows. The men express that type of behavior, knowledge of how to adhere and the possibility of attaining goals are motivating factors, such they are intrinsic motivated by being physical active alone or together with others. Both genders experience a high level of positive feelings and proudness when being physical active *"I get happy and the brain sends wonderful hormones into the bloodstream. I'm getting healthier"*.

They also experience a miner degree of negative feelings as sadness and failure when meeting obstacles which conflicts with their diabetes during their physical activity. *"I have struggled with high blood sugar levels today, they would by no means lower."* Such confirming Ryan and Decis' Intrinsic motivation theory.

4.4 Self Efficacy

The respondents inform that in general their self-management of their diabetes is good and therefore their diabetes is well regulated. Such they express possessing a high level

of self-efficacy. This explains the level of 82% of the respondents not measuring blood sugar, hence they trust in experience instead of measuring when being physical active.

3 domains in which the respondents answer they tend to forget adhering with their diabetes was identified as: forgetting Dextrose, adjusting their insulin pump and forgetting blood sugar measurement during physical activity. "*Forget about measuring blood sugar, and lower the basal rate. Low blood sugar as a result. "Feeling defeat, frustration, waste of hard work when I have to eat" "By adjusting my pump. I get annoyed at myself*," this experience of failure could reduce people with diabetes' self-efficacy.

5 Discussion

The results from the study shows a difference between survey 1 and the ESM survey regarding if the respondents are physical active with 91% in survey 1 saying they are physically active while the data from the ESM survey showed that in the 3-week period only 79.2% was active. The difference here could be explained by the technical error we saw when answering survey 1 were some of the respondents could not select "NO" which affects the reliability of survey 1 and therefore the one could expect the number to be closer to 79.2% as reported in the ESM survey. In general, the results should be considered preliminary as 11 respondents in the ESM survey and 2 respondents' in the interview may not be considered a valid foundation for the creation of new knowledge. However, because of consensus in data from this survey and other research, further investigation in the subject is to be considered.

The study indicated that men possess an intrinsic type of motivation for being physical active, which they express as a personal desire whereas woman expresses physical activity as a job to be done hence, they are extrinsic motivated using adherence of their disease as a factor for being physically active. 73% of the respondents reports their diabetes as well regulated in general, whereas 9% of the respondents are compliant with blood sugar measurements when being physically active due to a high level of perceived self-efficacy, such the people with diabetes relay on experience instead of blood sugar measuring during physical activity.

Three primarily domains in which the respondents express having issues with adherence when physically active were identified as (forgetting Dextrose) (adjusting their insulin pump) (forgetting blood sugar measuring during physical activity). When repeatedly forgetting to adhere with ones' disease it may affect the level of a persons' self-efficacy. According to Bandura the experience of failure reduces a persons' self-efficacy, the respondents informs having experiences like, failures, sadness, frustrations, shame and self-blame. According to Banduras' theory of self-efficacy the experiences of positive outcomes increases a persons' level of self-efficacy, Such a latent need for a tool reminding the people with diabetes to adhere within the three domains was identified, thus contributing to a positive experience within these domains which must be assumed to enhance the people with diabetes' self-efficacy, and therefore contributing to an even better regulated diabetes.

Developing a digital tool that can aid the people with diabetes with remembering to adhere to their diabetes, may help enhance the people with diabetes' self-efficacy if an enhancement of self-efficacy is proven doable, an increase of the people with diabetes'

motivation is to be expected, hence the experience of being competent, autonomous and relatedness enhances Intrinsic motivation. The informants from the interviews both express a reminding digital tool as a positive action for enhancing the people with diabetes' adherence with their disease. This correspond very well with Fogg's model of behavior change as the people with diabetes in general are very motivated and have the ability to test the blood sugar level, the only thing missing is the trigger. Contrary to suggested by [18] the respondents from the interview indicated that the wording of the trigger should be neutral in the expression but with an instructing message to measure blood sugar to create motivation to carry out the measurement. Both informants express that an image or symbol would be faster to decode than text, such the pictures or symbols need be within the diabetes discourse. The need for different types of modalities were also identified such as auditory, visual and vibration.

Results of the preliminary survey, and the interviews conducted in this investigation suggests that the respondents would prefer a digital wearable fitness tracker like a watch or a bracelet to manage their diabetes, such avoiding the feeling of stigma, and minimizing the risk of forgetting the tool, because one is wearing it on the wrist.

6 Conclusion and Recommendations

Based on data from this paper and other similar research it was concluded that most people with diabetes are being physical active. The study indicate that men in general are more intrinsic motivated to be physical active while woman a more extrinsic motivated. While the respondents express that they comply with the recommendations regarding registration of blood sugar, we found that many people with diabetes fail to adhere with recommendations for blood sugar measurements during physical activity, since only 9% of the respondents fulfilled the recommendations. Overall there is three domains in which people with diabetes tend to forget adhering with their diabetes: Forgetting Dextrose, adjusting their insulin pump and forgetting blood sugar measurement during physical activity.

Based on the findings we suggest a digital tool to remind the people with diabetes to measure their blood sugar. The digital tool should be based on the design of a fitness bracelet due to the wearability and because this is relative neutral and can worn without stigmatizing the people with diabetes. The wording of the trigger message should be neutral in the expression but with an instructing message to measure the blood sugar level. It is recommended that the digital tool has a display that can visualize text and pictures, such it is possible to decode a message by using a picture or a symbol, which sometimes are easier to interpret than a text message. It is necessary that the symbol relates to the diabetes discourse.

Multimodalities like vibration, auditory functions and visual effects are recommendable such providing the possibilities of personalizing the product.

In the attempt of enhancing the people with diabetes' self-efficacy and intrinsic motivation further investigation of what motivates men and woman are recommend hence men and woman are motivated by varies factors. The knowledge of knowing the motivational factors could be a helpful tool when designing the tailored message.

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