SOCIAL MEDIA AND GAMES AS SELF-MANAGEMENT TOOLS FOR CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

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Abstract: INTRODUCTION: Insufficient treatment of Type 1 Diabetes Mellitus (T1DM) can cause unpleasant and dangerous short-term complications, and disabling long-term complications. Children and adolescents are often associated with poor blood glucose regulation and poor treatment adherence. Motivating this group into achieving better illness knowledge, self-management and treatment adherence is difficult through ordinary diabetes education methods, which necessitates the need for alternate methods. METHODS: Health educational video games and social media are investigated as potential platforms for providing diabetes education and motivation. Publications were reviewed in order to estimate clinical and personal effects. RESULTS: 6 publications on children and adolescents’ use of health educational video games displayed increased patients knowledge regarding their illness and treatment hereof, improved treatment adherence and positive clinical results. Social media is identified in 2 publications as a promising platform for online communities, where patients and next of kin can seek advise, help others and share experiences. DISCUSSION: Video games and social media constitute platforms that children and adolescents are familiar with, engage in and enjoy and are for diabetes educational purposes. Tromsø Telemedicine Laboratory propose that by combining these platforms to make a social game experience that educates children and adolescents and motivates them conduct self-management and achieve better clinical results, thereby lowering their risk of diabetes complications.

1 INTRODUCTION

1.1 Type 1 Diabetes and Young People

Type 1 Diabetes Mellitus (T1DM) in children and adolescents is becoming a larger concern worldwide, with global incidence of T1DM for children increasing 3% annually. The incidences varying from intermediate to very high in European countries as Sweden, Norway, Finland, and UK and in Canada and New Zealand. T1DM is the dominant type of diabetes in the US amongst young people.(Dashiff, Hardeman and McLain, 2008)

The treatment of T1DM is symptomatic and complex, with the goal of regulating food intake, physical activity and administering insulin (Anderson et al., 2009), in order to keep daily blood glucose levels between 4 – 8(10) mmol/L and HbA1c <7.0% (may vary slightly from country to country). Due to the complexity of the treatment, children and adolescents may not be able to comprehend the treatment (Schilling, Knafl and Grey, 2006), and are therefore assisted by their parents to perform and adhere to the treatment (Dashiff, Vance, Abdullatif and Wallander, 2009; Lewandowski and Drotar, 2007). However, the transition from child to adolescent has become
synonymous with decreasing treatment quality and adherence (Waller, Eiser, Heller, Knowles and Price, 2005; Piazza-Waggoner et al., 2008). A study in the UK show that only 14-20% of children and young people reach the goal of HbA1c <7.5% (Christie et al., 2009).

Poor treatment quality can result in short-term complications for the patient, such as aggressive/violent behaviour, confusion, discomfort, anxiety and in extreme cases coma (Boyle and Zrebiec, 2007) possibly resulting in brain damage or even death, if the patient is not helped (Cryer, Davis and Shamoon, 2003). Over time, insufficient treatment also increases the risk of long-term complications such as blindness, kidney disease, neuropathies, amputations and elevated risk of heart attack and stroke (DCCT, 1993). It is therefore important to teach children with T1DM from young age about their disease, what affects it, and how to treat it. An early understanding of the condition, its treatment and motivation to adhere to the treatment may result in better glycaemic control and lowered risk of short- and long-term complications.

The poor results of today’s diabetes self-care for this group necessitate different methods of patient education. This statement is supported by Waller et al. (2005) in an analysis of 62 published papers on the topic of psychosocial and educational interventions for youths with T1DM. Waller et al. find the designs presented in the 62 papers to be poor and were unable to establish guidelines for appropriate education methods for young people based on these papers. The research community thus has a challenge of identifying alternative methods for educating children and adolescents with T1DM that also motivates them to perform better self-management and increased adherence to healthy treatment regimes.

1.2 New Potential Platforms for Delivering Diabetes Education

One method of educating and motivating children and adolescents with T1DM could be through the use video games. This media has over the years become one of the most popular forms of entertainment media (DeShazo, Harris and Pratt, 2010), and is engaged in by almost all teenagers (Lenhart et al., 2008) and approximately 60% of kids in the US aged 6 and above (Lieberman, 2001). A report made in 2005 by Roberts, Foehr and Rideout (2005) found that of the children and adolescents playing video games, 8-10 year olds on average spend 65 minutes daily playing video games, 52 minutes daily on average for the 10-14 year olds and 33 minutes daily on average for the 15-18 year olds. These findings support that video games is a medium that children and adolescents are familiar with, enjoy and engage in, and therefore constitute an obvious platform for delivering health related information and education.

Social media constitutes another potential platform for delivering diabetes education to children and adolescents, due to its widespread and popularity. The largest social media website as of autumn 2011 is Facebook, with over 800 million active users (FaceBook Official, 2011) and 20.6% of these listed and being under 18 years of age (Inside Network, 2011). This media makes it possible to reach and interact with larger groups of patients, who share the same interests. Social media should therefore also be considered a highly relevant media and investigated with focus on usage in health and diabetes related contexts.

A new popular trend for children and adolescents are video games available for free on social media web sites such as Facebook, where casual gameplay is combined with social media where players interact and build communities dedicated to said games. This combination of video games and social media constitute a potentially more desirable platform for educating and motivating children and adolescents for better self-management and treatment adherence. It is therefore important to investigate what could make social games successful and existing projects on the use of social games in patient health care.

In this paper, we present an alternative approach to traditional diabetes education of children and adolescents with T1DM. We propose to combine video games and social media, media which children and adolescents are familiar with, enjoy and engage in, with diabetes education. Using existing literature, the hypothesis that video games and social media can be used for health care purposes are each supported, and game design success criteria for a serious/educational game for children and adolescents are identified. The goal is to develop an educational video game, with social media interface for children and adolescents with T1DM. The game will utilize the captivating and motivating elements of existing successful social games and elements described in literature. The social game experience is intended to challenge the player to learn and improve self-management and treatment adherence, by performing virtual diabetes care, partaking in quizzes of diabetes related knowledge and competing with other players, using their own treatment data. All content will be based on quality
assured sources, acknowledged guidelines, diabetes modelling software and will be approved by experts.

2 METHOD AND MATERIALS

2.1 Literature Review

Existing literature on the use of video games for health educational and motivational purposes was examined, in order to determine whether this approach was usable for children and adolescents with T1DM and to determine factors that made existing healthcare educational video games successful. The use of social media, in patient health related contexts, was also studied in the literature review to determine the usefulness of this media. The literature review did however not include literature describing educational games with social media interface for people with T1DM, since it was not possible to identify any publications this subject.

The literature search was conducted in PubMed, using the following search enquiries and MeSH terms: Diabetes, Type 1 Diabetes Mellitus, Chronic Illness, Adherence, Self-care, Video Games, Serious Games, Computer Games, Educational Games, Social Media, Social Network, Facebook, MySpace, Children, Adolescents, Motivation.

All literature matching the search criteria underwent abstract reading, in order to determine relevance for this project. Papers not available in English were not included, nor were publications from which only the abstract could be obtained. Papers focusing solely on improving the diabetes care abilities of the parents/legal guardians of the child/adolescent with T1DM were also excluded from the literature discussed in this review. Review papers were accepted in the literature search.

The results of the literature search were divided into clinical effect studies of serious games and social media and studies which identified success criteria for serious games, e.g. how to make the gameplay appeal to the player and keep them motivated for playing.

In total, 8 papers were identified that fulfilled the established literature criteria. Of these 8, 2 papers addressed the use of social media and 6 papers, including review papers addressed health related video games for children and adolescents.

2.2 Analysis of Popular Social Games

In order to determine the success of current popular games on the social networking site Facebook, we examined the different elements of these games. Games that were chosen include FarmVille, Simply Hospital and educational games/mind training games such as Word Challenge and quizzes. Games that promote gambling, contains violence, sexual content or games that require a fee/paid subscription to play were excluded from the study.

3 RESULTS

The results of the identified studies and the review papers are presented in two sub-sections, addressing the clinical outcome of the studies and the identified success criteria for serious games.

3.1 Clinical Effects of using Serious Games and Social Media

Research by Lieberman (2001) estimates the effect of using serious games in a group of children and adolescents with T1DM compared to a control group. After 6 months, the intervention group showed a reduction in diabetes related urgent/emergency visits of 77%, whereas no change was detected in the control group. The study also reports that the children in the intervention group showed improved knowledge about their health and awareness of the risk factors of their illness, better daily self-care and monitoring, increased confidence about self-care as well as improved attitude towards prevention and better communication between child, parent and clinicians.

Baranowski, Buday, Thompson and Baranowski (2008) made a review of 27 scientific publications about 25 serious games for promoting health related behaviour changes, including diet-change games, physical activity change games, for people with disabilities and games for children with asthma and diabetes. The review shows that the majority of the publications demonstrate positive changes in patient health, as a result of engaging in serious games.

A review of 11 diabetes video games targeting people with T1DM, 10 of these targeting children with T1DM using a problem solving approach in their games, showed an increase in the players’ knowledge, adherence to self-care and clinical outcomes (DeShazo et al., 2010).

Other studies show that using video games for health educational purposes can yield positive results, such as improving treatment adherence, knowledge of disease and improved clinical outcome for children with Type 2 Diabetes Mellitus and obesity (Thompson et al., 2007) and

The literature search identified two studies reviewing the usage of Facebook by children and adolescents, for diabetes related concerns. The research, published in 2010 evaluates the content of diabetes communities on Facebook. The findings show that patients with diabetes, their family and friends use Facebook as a forum, in which they share experiences with others, give treatment advices and ask questions and receive feedback about diabetes related matters (Greene, Choudhry, Kilabuk and Shrank, 2010). Another study by Farmer et al. argues that younger patients become able to share and compare experiences with others, gain new knowledge about the disease and discuss side effects of their treatment with others (Farmer, Bruckner Holt, Cook and Hearing, 2009).

Of the reviewed literature, none displayed any ill effects of children and adolescents using either serious games or social media for healthcare related purposes.

3.2 Success Criteria for Serious Games

In the study by Lieberman (2001), two games were designed and implemented, one for children with asthma and one for children with T1DM. The study identified the following 7 elements as motivating factors for improving health behaviour (Lieberman, 2001): (1) Having an attractive role model who demonstrates appropriate self-care; (2) Being able to customize the self-care regimen of the players’ character to match that of their own; (3) Tests of the player’s self-care and preventive skills; (4) Supportive and informative feedback on choices the player makes in the game; (5) Having a log for the player’s character, containing the same elements that the player’s own log has, e.g. medication, activity etc.; (6) Supporting two-player gameplay; and (7) being able to choose game languages (Lieberman, 2001).

The review by Baranowski et al. (2008) also identifies elements to help improve a serious game, by analysing the recommendations in the literature. Baranowski et al. define two different approaches, which potentially promotes health behaviour change based on their literature: (1) Make behaviour change a process of playing the game, e.g. having goals; and (2) Implementing behaviour change concepts into the story of the game.

Hsu, Lee and Wu (2005) mention 6 fun factors in action games: (1) Novelty and powerfulness, (2) appealing presentation, (3) interactivity, (4) challenging, (5) sense of control, and (6) rewarding.

3.3 Review of Game Mechanics in Popular Social Games on Facebook

Utilizing the knowledge established in the literature review of video game elements, social media and factors that help make a serious game successful, it was possible to identify three characteristics of the social games and quizzes analysed in this paper:

(1) The games involve learning skills and planning actions/activities to achieve the best results. This can include planning the most cost-effective crop and when to plow, seed and harvest at a virtual farm or how to coordinate the work-shifts, maintenance and research at a virtual hospital. In order to progress or achieve better results quicker and cheaper, the player must actively learn the different aspects of the game mechanics and learn to plan ahead.

(2) The games are popular and keep being played, because they reward the player, which is supported by the findings of Hsu et al. (2005). Players are given virtual rewards for their achievements, e.g. mastering a certain skill/crop or learning to perform a new medical procedure. These rewards can be shared on the players Facebook profile for others to see, e.g. “Thomas mastered fly-fishing at level 3” or “Susan is building a new radiology unit”.

The rewards mechanics and progress motivates the player to keep playing and doing better and receiving new rewards. This can motivate others to do better and can build a community, where new less experienced players seek advice from the more experienced players with much routine and knowledge about the game and its mechanics, as supported by Greene et al. (2010).

(3) The games also use status sharing for other purposes, such as challenging other Facebook users or to ask them for their aid, e.g. “John beat your record at Crazy Taxi. Click to try to reclaim your throne” or “Alex’ crops need fertilizer. Click to go to Alex farm and help out”.

(1) and (2) motivates the player to do better in his/her game, by addressing other players’ desire to compete with the new record holder, about being the better farmer, physician or others. (3) addresses the other players’ desire to help others, by offering them to help out a person, which will benefit the player in need of help and also the player helping, who can see how helping made a difference, and potentially receive a reward for being helpful.
4 DISCUSSION

The use of serious games for children and adolescents are recommended in several scientific publications, which also identifies positive clinical outcome of these systems (Baranowski et al., 2008; DeShazo et al., 2010; Kato et al., 2008; Lieberman, 2001; Thompson et al., 2010; Thompson, Baranowski and Buday, 2010; Thompson et al., 2007). Despite these positive results, some studies agree that more research is needed, about what makes a game successful and what specifically initiates the player to make a change in their behaviour concerning their condition (Baranowski et al., 2008; Thompson et al., 2010; Thompson, et al., 2010b).

The popularity of video games and potential clinical outcomes suggest utilizing a video game approach to prepare children and adolescents with T1DM for handling their disease unsupervised, which will become necessary eventually, as they grow older. The clinical applications for social media in T1DM and the general popularity of this media also suggest this as a potential platform for T1DM education.

The authors believe that the success of each media could be combined to form more effective and helpful diabetes education applications. This could be in form of a diabetes-oriented game that utilizes addictive casual game-play, combined with a reward/achievement system and a social media interface for interacting, helping and competing with other players. The patient outcome of this could be better insight into their condition, improvement of self-management and increased adherence to their treatment.

Such games could also appeal to youths without T1DM, and thus increase the general insight in the population about T1DM, how it is treated and how to react in a situation where a person with T1DM requires help, e.g. in case of severe hypoglycaemia.

We propose a video game that lets the player engage in four different types of mini games of different nature:

1. Counselling: The player takes the role of an adviser/diabetes nurse/specialist.
   - In this part of the game, the player will take the role of a diabetes nurse/specialist/adviser, who helps patients on a daily basis. Each patient will present a different situation/problem that they need help with.
   - The player will be able to see recent blood glucose measurements, dietary information, ask the patient questions, and based on this, give advice to the patient. Based on the actions performed, the player will be rewarded points and achievements and the virtual patients will be either happy or unsatisfied with the help they received. The points and achievements received can be posted on a leaderboard and to the players Facebook account, and it can be shared with other people playing the game.

2. Avatar: A part where the player follows and controls a person with T1DM for a virtual day/week
   - In this part of the game, the player is assigned a virtual person with T1DM. The player will follow the person for a virtual day/week and have control of when the person measures their blood glucose, eats, administer insulin and is physically active. After the virtual period is over, the player will see how well they did in applying treatment to the virtual person with T1DM and receive points and achievements based on their performance. Their point score and achievements for this part of the game can also be shared via Facebook.

3. Mixed reality: Players enter their own blood glucose values, physical parameters, nutrition data, etc. The player is thus actively taking part in the game and competes with the artificial avatars (see pt.2) and other physical players, about being better regulated.

4. Quiz: Through answering different quiz the player is educated in diabetes treatment.

4.1 Counselling

In this part of the game, the player will take the role of a diabetes nurse/specialist/adviser, who helps patients on a daily basis. Each patient will present a different situation/problem that they need help with. The player will be able to see recent blood glucose measurements, dietary information, ask the patient questions, and based on this, give advice to the patient. Based on the actions performed, the player will be rewarded points and achievements and the virtual patients will be either happy or unsatisfied with the help they received. The points and achievements received can be posted on a leaderboard and to the players Facebook account, and it can be shared with other people playing the game.

4.2 Avatar

In this part of the game, the player is assigned a virtual person with T1DM. The player will follow the person for a virtual day/week and have control of when the person measures their blood glucose, eats, administer insulin and is physically active. After the virtual period is over, the player will see how well they did in applying treatment to the virtual person with T1DM and receive points and achievements based on their performance. Their point score and achievements for this part of the game can also be shared via Facebook.

4.3 Mixed Reality

When the player has learned to compete with the avatar, he/she will get the opportunity to actively take part in the game with his or her own data. In a mixture of avatars and real user/players, the players can compete with each other as well as the avatars, about being better regulated. This requires that the metabolism models and other physical models, which avatars are based on, should be as realistic as possible. As for the avatar module, the point score and achievements for this can be shared via Facebook.

4.4 Quiz

This part will consist of quick quizzes with predefined multiple-choice answers. Players will be presented with various questions about T1DM. This could vary from “What to do in this situation?”,
“Why is it important to …”. Other questions could be “Guess the next blood glucose value” and “Complete the blood glucose curve”. In the latter, the player will be presented with a picture of a blood glucose development curve plus food and insulin intake. The player could have three pictures to choose from, which each shows a different outcome. The player is asked to select the correct one.

Based on how the player answered the questions, points and achievements will be given, which can be shared on Facebook and a leader board. The player, if they beat someone’s record, can issue a challenge to other players, challenging them to beat the new record.

4.5 Scenario Materials

The scenarios for the four parts of the game will be based on actual data from a current study of 30 T1DM patients and textbook material on T1DM and through simulations, using the DIASnet Blood Glucose simulation algorithm, developed in a research project at the University of Aalborg, Denmark (Cavan, Everett, Plougmann and Hejlesen, 2003; Hejlesen, Plougmann and Cavan, 2000). Researchers and clinical personal must approve all scenarios.

4.6 Pitfalls of using Social Games as a Platform for Diabetes Education

Despite the literature displaying positive results and suggesting use of video games and social media as platforms for patient health care related projects, there are potentially pitfalls with using these media.

Publications on serious games generally display the effects of these when being actively used in studies, but not whether these games are able to compete with commercially available games. It is important to consider this competition, since a serious game will not be played, or they are played at lower frequency, once the study is over, thus lowering their usefulness. When designing serious games, the competition comes from game companies with larger budgets, more experience and manpower, an established name and fan base and a professional marketing section. It should therefore be considered to change the target audience in this project to not include adolescents that have the high standards of commercial games, but children aged 7-12 that are more likely to accept simpler casual games, such as social games. The game(s) should therefore be designed and developed with focus on resembling and competing with simpler casual social games.

Social media are suggested as a beneficial platform in T1DM related projects and the project group did not encounter any ill effects. There is however a concern of the quality and correctness of the content shared in social media. This is a relevant concern, since it is often the community itself that provides the content, often with no review from health care professionals or specialists. Incorrect information and wrongful recommendations can therefore occur, which potentially poses a risk of patient hazards. In order to include social media in patient focused projects, it is therefore necessary to define and control the type and content of user-to-user communication and interaction, if any. Having no restrictions could result in presence of information that could potentially be harmful for patients.

5 CONCLUSION AND FUTURE WORK

Children and adolescents with T1DM constitute a group that often experience insufficient treatment regimens. In order to improve knowledge of this group about their condition, their treatment and motivate them to improve treatment adherence, an alternate method of providing diabetes education is required. Health educational video games have shown improved treatment knowledge and clinical results in children and adolescents with T1DM and other chronic diseases, and social media is shown to be a promising platform for forming communities, for patients with diabetes and their family and next of kin. This recently initiated project at Tromsø Telemedicine Laboratory currently focuses on combining video games and social media, into T1DM educational video games with social media interface for children and adolescents with T1DM. These games will through different gameplay educate and motivate the player to learn about their condition and to improve their treatment and treatment adherence, and thus potentially help this group avoid short- and long-term diabetes complications.

In order to avoid potential pitfalls of video games and social media for the presented use case, future work includes additional in-depth studies and analysis of video game design for children and design of social games for children. One or more serious social games will be designed for one or multiple platforms. The video game(s) will be based on scientific literature search, game development literature, in cooperation with diabetes nurses and -
specialists, children and adolescents with T1DM and potentially interest groups such as the Danish and Norwegian Diabetes Association.

The project will evaluate clinical outcome of children and adolescents with T1DM using serious video games with social media interface. HbA1c will be measured before and after use of the game(s), to determine any improvements. Personal experiences and outcomes for children/adolescents and their close families will also be examined, by conducting interviews with participating children and adolescents and their families. The project will be conducted over a period of 3 years as a PhD-study (2012-2015), aiming to contribute in the field of serious gaming and diabetes self-management.

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