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THE ROLE OF PSYCHOLOGICAL FACTORS IN THE ADAPTATION PROCESS TO TYPE 1 DIABETES AMONG ROMANIAN ADOLESCENTS

PhD Thesis Abstract

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CLUJ-NAPOCA
2020

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Chapter 1. Introduction

1.1. General Overview of Type 1 Diabetes in the Context of Adolescence

Adolescence represents a period of time marked by important changes in all areas of growth: physical/sexual, cognitive, emotional, and social development, yet this challenging developmental stage can be amplified by being diagnosed with a chronic disease such as type 1 diabetes (T1D). Even if the causes of T1D are unknown, it requires a life-long management with insulin therapy (WHO, 2016). A chronic disease such as T1D has an impact on a physical level, affecting the function of the pancreas, but also affects psychosocial aspects of one's life. Therefore, the management of T1D requires both biological and psychological management.

1.2. Behavioral and Psychological Management of Type 1 Diabetes

Self-management of diabetes implies a daily set of self-care behaviors: the insulin treatment is required before every meal and the dose of insulin is established in relationship with the glycemia value. Maintaining a good glycemia value during the day can prove a tiresome process because there are many other factors that can influence it. Some of these factors can be controlled by the adolescent, such as the number of carbohydrates intake, the level of physical effort, the time between meals, while factors such as hormone changes are difficult to manage, also known as "the dawn phenomenon" (Carroll & Schade, 2005).

The main emotional difficulties associated with poor glycemic control in teenagers are depression, anxiety, sadness and withdrawal (Northam, Matthews, Anderson, Cameron, & Werther, 2005; Dantzer, Swendsen, Maurice-Tison, & Salamon, 2003). Even though these emotional difficulties can resolve within the first year after diagnosis, the coping strategies developed within this period of time can impact the later psychological development (Northam et al., 2005).

1.3. Relationship Dynamics in Diabetes Management

The management of diabetes is embedded in family and peer dynamics. The main goal in youth diabetes care is to ensure the transition of care from the family to the adolescent while enabling family and peer interactions. There are no guidelines for how the family should divide diabetes management, but the main focus is on shared responsibilities between family and adolescents (Markowitz, Garvey, & Laffel, 2015). In comparison, there are mixed results regarding the effect of peers on treatment adherence. Some studies show the beneficial effects of friends (La Greca, Auslander, Greco, Spetter, Fisher Jr, & Santiago, 1995; Ashraff, Siddiqui, & Carlineă, 2013) while others report a deterioration in diabetes control when adolescents with T1D interact with their friends (Skinner, White, Johnston, & Hixenbaugh, 1999; Palladino & Helgeson, 2012).

1.4. Improving Diabetes Management: The Efficacy of Different Types of Interventions

The value of the A1C is regarded as the main indicator of a good metabolic control, while on the other hand, behavioral and psychological aspects associated with diabetes are rated as secondary outcomes. It seems like the complexity of diabetes management is measured through a single value (A1C), rather than in an integrative manner that considers both medical and psychosocial factors. However, there are a number of intervention characteristics of that have larger effect sizes. Extensive research has shown that interventions that include a multi-component view rather than an educational one, they target modifiable diabetes or family factors rather than a specific self-care behavior, and they are delivered immediately after the diagnosis (Hood, Rohan, Peterson, & Drotar, 2010; Savage, Farrell, McManus, & Grey, 2010), use skills training programs and have a family-based and multisystemic therapy approach are the most effective for youth with T1D (Hilliard, Powell, & Anderson., 2016). Interventions using the cognitive-behavioral approach showed improvements in psychosocial well-being rather than in the glycemic control (Serlachius et al., 2016). Peer group support interventions

and group-based training showed to be effective in improving glycemic control and quality of life for adolescents with T1D (Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999).

1.5. The Role of Medical Devices for Diabetes Management

Even though in the context of rapid technological improvements of medical devices such as, continuous glucose monitoring (CGM) and continuous subcutaneous insulin infusion (CSII), there is still a lack of systematic evidence on how they contribute to A1C target levels and quality of life. Using CSII in children and adolescents is associated with small mean reduction in HbA1c and a decreased risk of severe hypoglycemia when compared with MDI (Gane, White, Christie, & Viner, 2010; Naranjo, Tanenbaum, Iturralde, & Hood, 2016). There is a polarization between expectations and experiences of using a medical device between adolescents and parents (Hussain, Akle, Nagelkerke, & Deeb, 2017), as well as the level of transfer of responsibility from parent to adolescent prior to making the decision to integrate a medical device in the daily care of diabetes (Rashotte et al., 2014).

1.6. The Healthcare Context of Type 1 Diabetes in Romania

There are more than 3400 children diagnosed with type 1 diabetes in Romania, while the Romanian health program only includes 280 insulin pumps, 500 glycemia sensors, and 100 insulin pumps incorporated with a glycemic sensor. The access to healthcare services in Romania focuses on medical care and there is a lack of psychological support groups or interventions. There is a lack of studies addressing the perceived satisfaction with diabetes care for adolescents within the Romanian medical context.

1.7. Rationale of the Present Thesis: The Role of Psychological Factors in the Adaptation Process to Diabetes among Romanian Adolescents

The main goal of the present thesis is to provide greater specificity concerning the factors that influence emotional well-being and metabolic control. Therefore, we used the theoretical framework of The Childhood Adaptation Model to Chronic Illness: Diabetes

Mellitus - The Revised Model (Whittemore, Jaser, Guo, & Grey, 2010). The framework suggests that individual and family characteristics, such as age, socioeconomic status, race/ethnicity, and treatment modality (pump vs. injections), psychosocial responses (depressive symptoms and anxiety), and individual and family responses (self-management, coping, self-efficacy, family functioning, social competence) influence adaptation. In this model, adaptation has both physiologic (metabolic control) and psychosocial (QOL) components (Whittemore et al., 2010). The studies included in this thesis, are also guided by two principles: the complexity theory (Cooper & Geyer, 2009) highlights the fact that living with T1D as an adolescent represents an emergent process, showing that the meaning of diabetes goes beyond an endpoint, i.e., metabolic control; the transition of care perspective (Dovey-Pearce & Christie, 2013) offers an in-depth view regarding the impact of the pubertal growth and developmental processes on diabetes management. Using these combined frameworks in an understudied population such as Romanian adolescents with T1D can bring valuable country-specific insights and it can also extend the existing body of literature regarding the psychological factors associated with diabetes management during adolescence.

1.8. Aims of the Present Thesis

The present thesis is composed by four studies and each chapter addresses a specific goal concerning our topics of interest, while all chapters remain connected in an effort to better understand the role of psychological factors for the adolescents' experiences of living with diabetes. Chapter 2 explores the views and ways of adapting to living with diabetes as an adolescent in the Romanian context. Chapter 3 extends this aim and focuses on the relationship between adolescents 'illness representations and their coping strategies, taking into consideration their emotional responses related to diabetes management. Chapter 4 aims to contextualize the usage of medical devices in the management of type 1 diabetes in Romania by exploring the views of adolescents, parents, and medical doctors. Finally, chapter 5 examines

the effectiveness of a combined intervention to improve diabetes management among adolescents.

The first study (**chapter 2**) used a qualitative approach in order to offer an in depth understanding of the teenagers' lived experiences regarding the interplay between physiological and emotional needs of diabetes during adolescence. There is no standard definition on how to better adapt to diabetes. It is well known that the main focus after the diagnosis is to learn how to manage the illness in terms of self-care behavior. Despite recent advances in these high-tech electronic devices, the rates of adolescents with poor metabolic control remain unacceptably high (Peyrot et al., 2005). Moreover, efforts to have a good metabolic control do not always count for predictable results. Living with diabetes is about being adherent to the medical treatment and equally about adjusting to emotional and behavioral problems that can have a negative impact on metabolic control (Frank, 2005). Although diabetes self-care behavior is demanding, with an emphasis on how food, medications, and exercise affect glucose levels and risks for co morbidities, interpersonal relationships play an important role in the management of diabetes (Ritholz, Beverly, & Weinger, 2011). Consequently, the present study wanted to explore the experience of living with type 1 diabetes in order to understand *how, when and why* adolescents integrate the interplay between behavioral and psychological aspects of diabetes.

We used an interview guide that served as a general framework for the discussions with 11 adolescents with type 1 diabetes, aged between 13 to 16 years. The interview was opened by posing the very broad question, "*What is it like to take care of your diabetes now that you are ... years old*?" Follow up questions were used to encourage the adolescents to talk about: what are the facilitators and the barriers in terms of following the regime; how they perceive the role of their family, friends, and medical professionals in relation with self-care behaviors; how they deal with decisions about diabetes management. This study used a qualitative design based on the thematic analysis proposed by Braun and Clarke (2006), highlighting an approach

that considers meaning across the whole data set, semantic theme. They were reviewed at two levels: at the level of the coded data extracts and then in relation to the entire data set. The interview findings are described as themes that highlighted the on-going process of adaptation for adolescence living with type 1 diabetes. Four themes were identified: *making sense of diabetes; normalizing diabetes; gaining control over diabetes; if I take care of diabetes, diabetes takes care of me*. This approach offered us the opportunity to understand not only the barriers to diabetes self-management but also the larger daily context in which these routines are immersed and how adolescents make sense of these experiences.

All themes identified serve to support and promote an overarching theme, that of learning through experience in order to gain a sense of control over diabetes. Despite different ages or lengths of time since diagnosis, adolescents living with diabetes shared complex experiences. Consistent across the adolescents in this study, making sense of diabetes illustrates the adjustment process to a new reality. The findings provide a framework for understanding on how adolescents integrate the interplay between behavioral and psychological aspects of diabetes, which can further have implications for practice. Specifically, taking into consideration the dual demands of diabetes can lead to insights on adaptation as a process. While the physical consequences of chronic illness have been well documented in the literature, the value of this study is that sheds light on the daily struggles of adolescents with type 1 diabetes. Sharing how they find solutions in order to cope with illness illustrates a picture beyond self-care behaviors in diabetes. To our knowledge, this is the first qualitative study in Romania that highlights the experience of living with type 1 diabetes in adolescents. It can have a particular significance in the context of Romania's health policies because it allows healthcare professionals to pay attention to the individual needs in order to maximize self-care management therefore tailoring the interventions in order to promote a good metabolic control.

This understanding is important because it highlights the need of emotional comfort in the management of diabetes.

Chapter 3 builds on the Common-Sense Model of Illness Regulation (Leventhal, Meyer, & Nerez, 1980). Illness representations (IR) refer to those beliefs that patients themselves use to best describe their own experience of illness and its management. There are five dimensions: *identity, cause, timeline, consequences, control/cure/treatment effectiveness* (Leventhal, Nerenz, & Steele, 1984). The Self-Regulation Model (Leventhal et al., 1980) states that there is a causal relationship between illness cognitions and coping behaviors. Even though there is an emphasis in investigating the influence of coping strategies on metabolic control or emotional well-being, little interest was raised upon the contributing role of the perceived efficacy of coping strategies in explaining differences in the variance in metabolic control and emotional responses in adolescents with type 1 diabetes. While adolescents might *use* a particular coping style in response to poor metabolic control, it is also important to highlight *how* efficient they believe that coping strategy is.

The aim of our study was to investigate the psychological factors related to differences in variance in metabolic control and emotional responses in adolescents with type 1 diabetes using the Common-Sense Model of Illness Regulation (Leventhal et al., 1980). Therefore, this study addresses the following aim: to examine the relation between IR, coping styles, perceived efficacy of coping styles, metabolic control, and emotional responses in order to test two mediation models. In the first model, coping styles and perceived efficacy of coping were expected to mediate the relationship between IR and metabolic control. In the second model, coping styles and perceived efficacy of coping were expected to mediate the relationship between IR and emotional responses. This potential mediating effect may offer a more comprehensive understanding of how the interplay between IR, coping styles, and coping efficacy influence metabolic control and emotional responses to illness.

This study employed a cross-sectional survey design. A sample of 66 participants (30 boys and 36 girls) aged between 12 and 16 years participated in this study. Participants completed questionnaires regarding illness representations, the frequency of use and perceived efficacy of coping strategies, and emotional responses during a routine diabetes appointment. Metabolic control was indexed via HbA1C levels in the last three months. Two alternative hypothesized models were tested with coping strategies as mediator for the relationship between illness representations and metabolic control, on one hand, and emotional responses on the other hand. Coping strategies only acted as mediators for the relationships between different dimensions of illness representations (timeline cyclical, consequences, emotional representation, coherence) and the dimensions of emotional responses (anger, sadness, nervousness).

To our knowledge, this is the first study that differentiates between the use and the perceived effect of a coping strategy. This framework proves important in the context of diabetes as a long-term (chronic) illness, meaning that coping strategies used by adolescents and their perceived effectiveness can change over time. Study results indicate that pushing adolescents to take independent decisions about diabetes treatment too soon after the diagnosis, can have negative emotional effects in the long term, i.e., feeling more sad or angry. If adolescents do not have a greater understanding of their emotions, presenting them with the possible negative complications of a poor metabolic control can lead to more risk-taking behaviors in the long term.

Chapter 4 emphasizes how recent developments in medical devices such as, glycemic sensors and insulin pumps, have heightened the need for a more in-depth understanding of how they are perceived in the daily management of diabetes during adolescence. Medical devices are becoming essential for the management of type 1 diabetes. The use of insulin pumps eliminates individual insulin injections allowing the delivery of a basal level of insulin

combined with larger doses before meals (continuous subcutaneous insulin infusion - CSII). The installation of an insulin pump requires medical expertise. Continuous glucose monitors (CGM) devices provide real-time glucose trends allowing caregivers to view their child's glucose readings on their own devices, including smartphones (Sherr et al., 2018). The installation of a CGM device does not require medical expertise and is usually installed by the parents or the adolescent.   Both use of CSII and CGM were shown to have a positive impact on glucose variability (Sherr et al., 2016; Massa, Gys, Bevilacqua, Wijnands, & Zeevaert, 2019), with mixed result when considering the impact on quality of life (Evert et al., 2016). Using the Personal Health Record (PHR) framework referring to the patient's competence and autonomy in interpreting the information based on the personal knowledge about their diabetes (Piras & Zanutto, 2014), the patient is considered a *diagnostic agent* (Andersen, Bjorn, Kensing, & Moll, 2011; Oudshoorn, 2008), and the health care specialist is assigned to interpret the health information (Piras & Zanutto, 2014). There are country-specific approaches to diabetes treatment and availability of therapies across the world. Regarding the access to specialized services, such as free of charge insulin pumps and the technology-specific training, Romanian diabetes program covers only 30 new patients annually (Donicova, Broz, & Iocara, 2011).

The present study aims to contribute by providing an understanding of what it means to integrate a medical device in the diabetes management of Romanian adolescents. In-depth semi-structured interviews were conducted in Romania with five adolescents, their mothers, and two medical doctors specialized in diabetes. Each participant described their experience of managing diabetes with the help of medical devices. The interviews were audio recorded and transcribed verbatim. Data was thematically analyzed.

The triangulation of perspectives allowed the identification of major themes for each group. Two themes emerged for the adolescent's perspective: *Building Trust in the Technology and Dealing with Glycemic and Emotional Variability*; one for the parent's perspective:

Medical Devices: Hopes and Worries; and one theme for the medical doctor's perspective: *Redefining the Medical Expertise*. Results provide relevant insight into the perceptions of all actors involved in the process of integrating technological medical devices into diabetes management. Parents are oriented *to solve the problem of metabolic control by using a device* while adolescents discover *their needs* regarding diabetes management. This process can lead to emotional conflict between parents and the adolescent. Our results are similar to other qualitative studies showing that parental involvement is an important predictor of good metabolic control (Olinder, Nyhlin,, & Smide, 2011), but it can be perceived by adolescents as intrusive when there are frequent inquiries and direct guidance, leading to poor self-management of diabetes (Rashotte et al., 2014). Our findings show that adolescents are not encouraged to talk about their emotions. Furthermore, parents are over-stepping their role in the daily management of diabetes even though there is a medical device to ensure glycemic balance. In the context of personal health information management, the role of the medical team is changing. The present results are consistent with previous studies showing that there are two areas of expertise in managing diabetes: the one of adolescents and their families and that of medical doctors (Olinder et al., 2011; Rashotte et al., 2014).

To our knowledge this is the first study to explore the perceptions of Romanian adolescents, parents and doctors concerning the use of medical devices for diabetes management. Concerning the integration of insulin pump, there is a need to implement a hospital discharge protocol incorporating knowledge evaluations regarding the usage of the insulin pump, and addressing the emotional difficulties associated with wearing it. There is also a need to train medical professionals to recognize the emotional difficulties of the patient living with diabetes and how it can have a negative impact on metabolic control. Overall, present results highlight the need to evaluate the readiness for making and sustaining changes to accommodate a medical

device in their treatment, both for adolescent and the parent. Moreover, setting realistic goals for the role of the medical device in the treatment of diabetes is of greatest importance.

Chapter 5 highlights the importance of a combined intervention aiming to improve adolescents' diabetes management. A good management of diabetes is more difficult during adolescence compared to other life stages (Sherr et al., 2018) despite the recent advances in the medical understanding of type 1 diabetes that have provided patients with an increased perceived control over their diabetes management (Shan, Sarker, & Martin, 2019). Interventions have evolved from a specific focus on the medical treatment to a more patient-centered care (Mensing & Norris 2003). There is a gap in the literature regarding the efficacy of an integrated intervention which combines psychosocial interventions with medical nutrition therapy. Furthermore, although there are numerous randomized control trials showing the efficacy of psychological interventions in improving treatment adherence for children and adolescents (Snoek & Skinner, 2002; Harvey, 2015), there is still a lack of studies exploring the experiences of adolescents enrolled in psychotherapeutic groups that focus on obtaining better psychological and metabolic control. Therefore, the present pilot study applied quantitative and qualitative methods to explore the effectiveness and the participants' subjective perception of a combined intervention. The intervention included group-based cognitive-behavioral therapy (G-CBT) with medical nutrition therapy (MNT) to improve psychological and metabolic management among adolescents with T1D.

This randomized pilot study applied a sequential explanatory design with two phases: 1) to evaluate the preliminary outcomes concerning the efficacy of the intervention; 2) to evaluate the acceptability of the intervention using a semi-structured interview aimed to obtain the participants' feedback, thoughts and reactions about the combined intervention. A total of 21 adolescents qualified for the study, and following randomization 11 participants were assigned to the intervention group and took part in the intervention. The 10 participants who were

assigned to the control group received standard care from their regular diabetes clinics throughout the study and had no other contact with the research team. A pilot CBT-MNT group was conducted with a total of 11 participants. The group intervention consisted of 8 sessions. Each session lasted approximately 90 minutes. Sessions were held twice a month, over a 4-month period. Psychosocial and behavioral difficulties were targeted in each session in a combined manner.

In order to determine the preliminary efficacy of the pilot intervention, several measures of the blood glucose level (HbA1C) and psychological variables (quality of life; self-care; fear of hypoglycemia; self-efficacy for diabetes management; negative emotions related to diabetes) were included. We wanted to gain a better understanding of how the combined intervention was perceived by participants with extreme scores on the outcome variables (i.e. very high or very low scores). A multiple case study design (Stake, 1995; Yin, 2003) was applied for collecting and analyzing the data. Using this method served the purpose of "illuminating a particular issue" (Creswell, 2005 p. 439), such as the lived experience of the adolescents during the group intervention. This selection procedure resulted in a sample of five participants, namely three boys (13,15, and 16 years old) and two girls (12 and 13 years old). These five participants were invited for an individual follow-up session within a month after the intervention. The semi-structured interview protocol opened-up with the following question: *how was it like for you to participate in the intervention?* Several open-ended questions explored the general and specific feedback regarding the participation in the group intervention.

After the combined group intervention, mean levels improvements were found for all outcome measures. However, there were statistically significant differences in mean levels between the measurement points only for the variables of negative emotions related to diabetes, self-efficacy, and fear of hypoglycemia as a total score and the subscale related to worries. This shows that the intervention has an effect on these variables. Even though not statistically

significant, the partial η^2 of the other measures indicated small effects. However, this low power can be explained by the small sample size ($N = 11$).

Adolescents highlighted the importance of the group format in terms of togetherness and accepted feelings. During the intervention, adolescents learned to talk about their negative emotions without the urge to immediately change these. This contributed to their feeling of safety. In addition to disputing and restructuring negative thoughts and emotions, the present intervention focused on creating an emotionally safe space for the participants. Therefore, it helped them gain in terms of psychotherapeutic alliance and increase the intervention's efficacy.

Present results show improvements related to the decrease of negative emotions levels and fear of hypoglycemia levels and better self-efficacy after the intervention. This approach may support further group interventions in fostering an emotionally safe space in order to dispute and restructure negative thoughts and emotions that can negatively impact diabetes self-care. Using a mixed-method approach to collect data allows the development of a more participant-centered intervention protocol with results that can be maintained in the long-term.

All in all, the present thesis provided an in-depth view of what it is like to live with T1D as an adolescent, focusing on different psychological factors and relationship dynamics (with the parent and with the medical doctors) that have an impact on the daily management of diabetes. Taken together, this thesis adds to the limited evidence base within the Romanian context (Badescu et al., 2016; Serban et al., 2015; Bogatean & Hancu, 2004). The thesis shows that living with diabetes during adolescence is not a linear experience and the voices of the young people can inform researchers to develop tailored evidence-based interventions that help teenagers achieve better emotional and metabolic control.

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