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The Role of Family Functioning on Metabolic Control and Quality of Life in Adolescents with Type 1 Diabetes Mellitus

Ana Cristina Almeida, Engrácia Leandro and Maria da Graça Pereira

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Abstract

The incidence of type 1 diabetes mellitus (T1DM) in childhood and adolescents is increasing worldwide and diagnosis of type 1 diabetes represents an important stressful condition for families and adolescents. The maintenance of normal glycemic results requires adherence to self-care behaviors in order to prevent disease complications. However, diabetes self-care requires extensive and daily behavioral demands from adolescents that may interfere with their quality of life.

Parents have an important influence on T1DM' management, in adolescents. Family functioning is an important determinant of metabolic control and adolescents' quality of life. During adolescence, parents must transfer the responsibility for diabetes care to the adolescent and supervise diabetes management. Parental style and family conflict are related to glycemic control and quality of life in adolescents.

The main goal of this chapter was to analyze the relationship between metabolic control, quality of life and family functioning in T1DM adolescents.

Keywords: Metabolic Control, Quality of Life, Family Functioning, Type 1 Diabetes, Adolescents

1. Introduction

T1DM is one of the most common chronic illnesses in children and adolescents [1, 2]. This chronic disease and its serious complications forces both adolescents and families into an

abrupt lifestyle change and psychosocial adjustment [3]. An intensive daily glycemic control and treatment regimen have been associated with a better control of the disease, reduced complications and improved quality of life [3, 4]. T1DM self-management activities include metabolic control monitoring at least four times a day, frequent insulin injections (at least four times a day), adjustment of insulin doses to match carbohydrate intake and engagement in physical activities [1, 5]. Management of T1DM requires changes in the lifestyle of both the adolescent and his/her family, which can contribute to distress and diminished quality of life of both adolescents with diabetes and parents [6].

T1DM occurs when pancreatic β cells cannot produce insulin due to an autoimmune process which destroys these cells. The conversion of food into energy is abruptly interrupted, requiring an insulin therapeutic regimen to meet a person's need for insulin [3, 7].

In adolescence, individuals are confronted with biological, physical and psychosocial changes which indirectly affect their levels of glycosylated hemoglobin which tend to be high due to both the hormonal components of puberty and the transfer of responsibility for diabetes management from parents to adolescents [7, 8]. Adolescents with T1DM have been found to have worse metabolic control than individuals of other age groups which is associated with an increased risk of developing diabetes complications [9]. Adolescents play an ever-increasing role in diabetes management, according to their developmental acquisitions [5, 10]. However, adolescents' risk behaviors, such as those related with their sexual development, use of illicit drugs, smoking and alcohol, and the vulnerability to the development of mental health problems also compromise their metabolic and psychological outcomes [3, 5]. In the transition to adolescence, young people with T1DM tend to have poor self-management, which deteriorates metabolic control, increases psychosocial distress and negatively influences their quality of life [11]. The stress caused by the feeling of being different from their peers, as a result, of self-management activities which disrupt their daily activities, and the sense of guilt, over exhibiting poor metabolic results, may negatively impact adolescents' quality of life [12, 13].

The presence of a chronic illness during adolescence not only affects the adolescent, but also interferes with family functioning. Nevertheless, family also influences illness outcomes due to their communication patterns, interaction styles and problem-solving skills [14].

While building upon the model of childhood adaptation to T1DM [15], the aim of this study is to describe the relationship between family functioning, metabolic control and quality of life, in T1DM adolescents.

2. Adolescents with T1DM:: The process of adaptation

In adolescence, the experience of new cognitive and psychosocial competences and independence desires, by the adolescents, interferes with the relationship with their parents. This may influence adolescents' performance regarding diabetes management and, consequently, adolescents' process of adaptation to the illness itself [16].

As Butner and colleagues [16] point out in their study on the parent-adolescent's discrepancies with respect to diabetes management, adolescents tend to perceive themselves as more competent and independent than parents. This situation has an impact on the daily family diabetes activities and on the well-being of both parents and adolescents leading often to conflicts, conflicts, poorer metabolic control, well-being and, consequently, poorer illness adjustment.

The adaptation process to T1DM is complex for both adolescents and their families, and requires time and effort with regard to the daily treatment regimen [17]. The internal and external factors that influence the physiological and psychological adaptation process of T1DM adolescents have been largely recognized in literature and have been identified in theoretical childhood adaptation models in T1DM [6].

The Childhood Adaptation Model to Chronic Illness: Diabetes Mellitus [15] identifies factors that influence childhood adaptation to T1DM and posits that individual and family characteristics such as age, socioeconomic status, race/ethnicity, treatment modality, individuals' and families' responses – like self-management, coping, self-efficacy, family functioning and social competence – influence metabolic control and the quality of life of adolescents with T1DM, i.e., level of adaptation. The model allows the identification of modifiable risk and protective factors, in the adjustment process of adolescents with T1DM [15]. According to the Childhood Adaptation Model, metabolic control and quality of life of T1DM adolescents are considered key factors in the adaptation process to diabetes, and a good adaptation is dependent on good glycemic levels and a positive quality of life [5, 6]. Family functioning is considered a potential mediator of the stress felt by the children and their parents, caused by the presence of a chronic disease, and the family and child adaptation process to diabetes [15].

3. Metabolic control in adolescents with diabetes

Metabolic control is recognized as the most important marker of physiological adaptation to T1DM, but adolescents with this disease tend to show some difficulty in achieving it [7]. Optimal glycemic levels require the balance of dietary intake, physical activity and the adjustment of insulin doses [18, 19]. For T1DM adolescents, the American Diabetes Association (ADA) [20] recommends maintaining hemoglobin A1C values below 7.5% to prevent and delay medical complications, such as microvascular and neuropathic complications [20]. However, the metabolic control of T1DM adolescents presents suboptimal results (range from 7.5% to 9%) [21] which tend to increase the adolescent and the family stress levels, because they feel unable to achieve and maintain normal glycemic levels to prevent hypoglycemic episodes and long-term complications [22].

Metabolic control is measured by glycated hemoglobin, which represents the average over the last 2–3 months of blood glucose and is internationally recognized as the standard measure of metabolic control [7].

Individual factors such as pubertal development, disease duration and race/ethnicity, affect metabolic control of T1DM adolescents with type 1 diabetes [7]. Literature has suggested that

longer diabetes duration and pubertal development are linked to poor metabolic control in adolescents with diabetes [7]. During puberty, the decrease in insulin sensibility caused by growth hormone results in poor metabolic control among of T1DM [11]. Also, problem-solving skills of immature adolescents, and rebellion against parents' participation in diabetes management are linked to poor metabolic control [23].

However, metabolic control tends to deteriorate during puberty due to the independence and autonomy from parent's orientation in diabetes self-management and behavior changes during adolescence [7]. If parents continue to encourage their children to participate in their diabetes care during adolescence and participate in their children's diabetes treatments, adolescents will have better glycemic and psychosocial results [22]. Also, the level and type of parent involvement in adolescents' diabetes management must change according to the adolescent developmental stage to avoid family conflicts and consequently a negative impact on adolescents' metabolic control and quality of life [24, 25].

Regarding the role of metabolic control in the adaptation process of adolescents with diabetes and, according to the study of Malik and Koot [10], metabolic control was a predictor of the adjustment of adolescents to T1DM; however, the small explained variance in adolescent adjustment was interpreted as metabolic control having little influence on adolescent's adjustment to diabetes.

The association between metabolic control and quality of life in T1DM adolescents is controversial [26]. While some studies have found a link between higher metabolic control and lower well-being [27, 28], others did not find any relationship between metabolic control and quality of life, in T1DM adolescents [9, 29]. Literature has suggested that metabolic control was improved in adolescents who reported good quality of life, and who were supported by a stable and cohesive family with a clear defined sharing responsibility, in diabetes management [21].

4. Adolescents' quality of life and T1DM

Quality of life is recognized as one important psychosocial outcome in adolescents with diabetes [17]. The individual subjective experience of the impact caused by the illness and its treatment, on the physical, psychosocial and cultural domains of one's individual performance defines health-related quality of life [30]. The frequent measure of quality of life in T1DM adolescents is useful to understand how they cope with diabetes tasks and how they include care in their daily activities [30]. Moreover, in the monitoring of quality of life of adolescents, it is important to consider how the type of diabetes treatment, the diabetes symptoms, the social and emotional development of adolescents, and the adolescents' academic performance influences their quality of life [31].

T1DM adolescents tend to report good quality of life despite the complex process of disease management [29]. Quality of life in T1DM adolescents is also similar to the quality of life levels of healthy adolescents, in spite of their parents' perceptions [9, 31]. However, the diabetes

burden on routine activities and their impact on relationship with friends, interfere with emotional and social well-being of adolescents with diabetes, which may negatively affect the adolescent's quality of life [9, 13]. In their longitudinal study with Chinese adolescents with T1DM, Guo and colleagues [32] found a positive association between self-management care and satisfaction with quality of life. This fact may be explained by family support and self-efficacy influence in the relationship between self-care management and satisfaction with quality of life [17]. Kalyva, Malakonaki, Eiser and Mamoulakis [13] concluded that quality of life was better, in male adolescents with better glycemic control, shorter duration of diabetes and younger age at diabetes onset. In the same study, it was found that older adolescents reported better quality of life when compared with younger adolescents, and this result may be explained by the fact that older adolescents have more autonomy, in their diabetes management. Guo et al. [17] also found that diabetes duration had an impact on adolescents' quality of life, with less duration of diabetes predicting better quality of life. These findings may be explained by the dominant influence of parents on the adolescents' diabetes management [17].

The literature has suggested that metabolic control is a significant predictor of the adolescent quality of life [10], is associated with adolescent's adjustment to T1DM, and that quality of life of adolescents with diabetes is related to family support [33].

Literature has suggested that higher quality of life was related to better metabolic control in adolescents [21]. However, in adolescents with diabetes, quality of life may not be related to metabolic control, if soon after the onset of diabetes, adolescents and their families were integrated in intervention programs to develop and increase their ability to diabetes management [31].

In order to analyze the better quality of life successful prevention interventions in T1DM adolescents, Fogel and Weiss-Benchell [30] observed that some interventions, such as education sessions or motivational interviewing, improved quality of life in adolescents with diabetes, but without the concomitant results in their levels of glycemic control, which may explain the special relationship between quality of life and metabolic control, in T1DM adolescents.

5. Family functioning: The relationship with metabolic control and quality of life

In the complex process of diabetes self-management, adolescents and their families share the responsibility and decision-making process in the illness-related activities to achieve the goals of diabetes control and well-being [7]. Family functioning represents an important factor in the diabetes management treatment in T1DM adolescents and affecting metabolic control and quality of life outcomes [27, 34]. The study of Skinner, John and Hampson [35], that studied the relationship between family factors and metabolic control, including family functioning, concluded that family factors were predictors of metabolic control, accounting for 34% of the variance in metabolic control.

Table 1 shows some of the most important parental strategies to improve better metabolic control and quality of life in T1DM adolescents.

Parental Strategies to Improve Metabolic Control and Quality of Life in Adolescents with T1DM
<ul style="list-style-type: none">• Negotiation of parental supervision regarding adolescents’ diabetes management (food intake, glycemic control, adjustment of insulin doses and exercise);• Parental supervision of adolescent diabetes care, according to the developmental adolescence stage;• Gradually transfer diabetes care responsibility to adolescents when they demonstrated the adequate skills to deal with diabetes care tasks;• Support emotionally the adolescents when they felt unable to achieve and maintain normal glycemic levels;• Clear definition of the shared responsibility between parents and adolescents about diabetes management, to avoid parental overinvolvement;• Development of a collaborative family organization characterized by guidance and supervision from parents;• Clear and warm communication patterns between parents and adolescents related to adolescent diabetes care;• Development of skills to deal with the stress caused by diabetes care;• Development of stable, supportive and cohesive family interaction with adolescents;• Emotional support and positive reinforcement of successful adolescents’ diabetes management;• Avoid negative parenting behaviors such as hostility and conflicts about adolescents’ diabetes management.

Table 1. Parents strategies to promote better metabolic control and quality of life in adolescents with type 1 diabetes

Literature has suggested that family functioning was strongly associated with better metabolic control, psychosocial functioning and psychological adjustment in T1DM children and adolescents with type 1 diabetes [36]. Parents of children with diabetes, particularly mothers, tend to experience greater levels of psychosocial distress and adjustment problems due to the responsibility required by diabetes management on daily family activities [1]. Studies have demonstrated that higher family anxiety and less positive parenting strategies are linked to negative family perception about adolescent’s self-management, which may exacerbate adolescents’ neglected self-care and compromise their glycemic results [3]. Psychological adjustment problems in mothers of children with diabetes have been related to poorer psychological adjustment and higher levels of distress in T1DM children [37]. Other studies have found that negative family functioning increased conflicts between parents and children affecting negatively the child metabolic control, especially in older children [35]. Children’s developmental process with the acquisition of more competences and independence, regarding diabetes care, may be related with the maturation process of puberty [16, 35]. Pertaining to what may originate family conflict between T1DM adolescents and their parents, Fogel and Weissberg-Benchell [30] mentioned conflicts caused by what adolescents think they hear from their parents (nagging and criticism) when parents try to express worry and concern with the adolescent’s disease.

Family factors were related to adolescents’ metabolic control [7, 35] and quality of life [9]. Whilst, in one research about family influence on adolescents’ diabetes outcome, higher conflict between parents and adolescents were associated with poor metabolic control [34,

35], in another study, better family structure and positive parental emotional support were related to better metabolic control in T1DM adolescents [36, 38].

Although during adolescence, parents must transfer the responsibility for diabetes management into the adolescents, the literature has shown how parental monitoring and family support influence health outcomes in T1DM adolescents, in spite of their desire for independence and autonomy [34]. Literature has suggested that older adolescents have more risk to neglect diabetes self-management than younger adolescents, which makes parental involvement more crucial during adolescence [39].

However, the quality of parental support and monitoring is crucial, because when adolescents perceive that parents are overinvolved in their diabetes care and consider parents' guidance and control being too much, metabolic control tends to be negatively influenced [34, 40]. Also, Skinner, John and Hampson [35] observed that adolescents who perceived the relationship with parents more critical, unsupportive and negative regarding their diabetes management, showed worse metabolic control. Therefore, research advocates a collaborative family style, characterized by an appropriated guidance and control from parents, to improve metabolic control and quality of life in T1DM adolescents, and consequently a better diabetes adaptation [22, 35, 41]. When Faulkner and Chang [18] interviewed adolescents and their parents about what promoted better adolescents' performance, in their diabetes management, the results showed that a directive guidance (be an aid to perform) and tangible (physical) assistance were considered as being useful in improving metabolic results, in adolescents. Also family environment, characterized by warm, caring, and cohesive interactions between adolescents and parents, was related to better self-management, glycemic control and quality of life in young T1DM adolescents [18, 33]. In their study about observed parenting in T1DM adolescents and their mothers, Jaser and Grey [36] concluded that sensitive parenting behaviors and child-centered and positive reinforcement were related to better illness adaptation and better metabolic control, while maternal hostility, considered as negative parenting behaviors, was associated with worse metabolic control in adolescents. Also Monaghan and colleagues [42], in their study about the relationship between parents' stress, parenting style and self-care in T1DM pre-adolescents, concluded that greater parental warmth and flexibility were related to less parenting stress related to diabetes care, which contributed to the decrease of family conflict and, consequently, was related to the increase of pre-adolescents' adherence. However, these authors [42] did not find any association between authoritative parenting and improved metabolic control as observed among this parenting style and adherence. One reason for this fact may be due to glycated hemoglobin being on average under 8.0%, i.e., pre-adolescents who participated in this study showed a metabolic control recommended by ADA [20], for this age group, that delay medical complications.

Additionally uninvolved family style was related to poor self-management and poor quality of life [43]. When neither the parent or the adolescents assume the responsibility for diabetes care, or adolescents have excessive autonomy in diabetes management, adolescents presented worse metabolic control [18, 35]. For that reason, even during adolescence, the family must continue involved in diabetes management tasks, and the responsibility for diabetes care

should be gradually transferred to adolescent only when they demonstrate the maturity and the adequate capacities to lead with the diabetes management tasks [22].

Emotional support of parents and parental responsiveness were related with a better quality of life in adolescents with diabetes [3]. Also Jaser and Grey [36] emphasized the family influence on adolescents' quality of life, concluding that warmth and family caring behaviors were related to better quality of life in adolescents. That same study showed that observed intrusive parenting behaviors, like parental influence, were related to adolescents' quality of life and depressive symptoms. Furthermore, Pereira, Berg-Cross, Almeida and Machado [33] found that family conflicts were a predictor of less quality of life in adolescents with diabetes. Family conflict among T1DM adolescents and their parents were related to lower quality of life in adolescents [9] and were also associated with several psychological and behavioral outcomes in young adolescents with T1DM [34].

6. Conclusion

During adolescence, the balance between developmental struggles, challenges and family interactions represent a delicate and crucial component of a successful process of adaptation to diabetes that include an optimal metabolic control and a good quality of life, in T1DM adolescent.

Communication between parents and adolescents seems to have an important influence either on adolescent's adjustment to diabetes or in glycemic results or quality of life. Thus, interventions which allow the development of communication skills related to diabetes management in T1DM adolescents and their parents may decrease family conflicts and improve adolescent's metabolic control.

Interventions to develop self-management and decision-making in T1DM adolescents and their families also appear to be useful to improve adolescents' metabolic control and quality of life. It is important in order to improve adolescent outcomes, that adolescents develop their diabetes self-management skills and learn how to share diabetes responsibility with parents, without engaging in family conflicts.

Parents of T1DM adolescents must develop a collaborative parenting style with adolescents in their diabetes management and appropriated levels of guidance and control to improve adolescents' metabolic control and quality of life and, simultaneously, minimize family conflicts over diabetes management.

Author details

Ana Cristina Almeida¹, Engrácia Leandro² and Maria da Graça Pereira^{3*}

*Address all correspondence to: gracep@psi.uminho.pt

1 University of Minho, Social Sciences Institute; Braga, Portugal

2 Researcher at Centre for Research and Studies in Sociology, University Institute of Lisbon; Lisbon, Portugal

3 University of Minho, School of Psychology; Braga, Portugal

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