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FULL LENGTH MANUSCRIPT

Individual and Family Management in Portuguese Adolescents with Type 1 Diabetes: a Path Analysis

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Abstract

Background This study evaluates the adequacy of the Revised Self and Family Management Framework (Grey et al., *Nurs Outlook* 63:162–170, 2015) in Portuguese adolescents with type 1 diabetes and analyzes the effect of parental coping, family support, and adherence in the association between illness representations, school support, metabolic control, quality of life, and family functioning.

Method One hundred adolescents (aged 12–19) and their parents participated in a cross-sectional study. Adolescents were assessed on school support, adherence to self-care, family support, and quality of life. Parents were assessed on parental coping and family functioning. Both adolescents and parents were assessed on illness representations. Adolescent's metabolic control was evaluated through glycosylate hemoglobin.

Results Adolescents' and parents' illness representations were associated with metabolic control, quality of life and family functioning. Parental coping, family support and adherence had an indirect effect between illness representations and diabetes outcomes.

Conclusion Findings showed the adequacy of Grey and colleagues' model (*Nurs Outlook* 63:162–170, 2015) in adolescents with type 1 diabetes and how family support, parental coping, and adherence contribute to diabetes management. Interventions to improve adolescents' and family's management of Type 1 diabetes should be designed to change adolescents' and family's representations and enhance their ability and skills in diabetes management.

Keywords Adolescents with type 1 diabetes · Illness representations · Family coping, support, and functioning · Adherence · Metabolic control · Quality of life

Introduction

Type 1 diabetes (T1D) is one of the most frequent chronic metabolic disorders in adolescents [1], and its onset results from deficiency in the insulin secretion, insulin action, or both [2]. Despite the mechanism that triggers the destruction of the majority of pancreatic beta cells being still under investigation, T1D is considered an autoimmune disease that can be triggered by infections, diet, or toxins which a child may have been exposed during in utero development, during the perinatal period, or in the first years of life [3]. Therefore, adolescents with T1D and their parents must compensate the deficient functioning of pancreatic beta cells in insulin production, either by multiple insulin injections or by continuous subcutaneous insulin infusion [4]. The calculation of insulin doses requires self-monitoring of blood glucose levels several times per day as well as carbohydrate intake to maintain glycemic control and prevent microvascular and macrovascular diabetes complications [5]. During

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adolescence, building one's identity, independence from parents, and peer pressure may conflict with the daily demands of diabetes management (self-monitoring of blood glucose, monitoring of carbohydrate intake, administration of insulin doses according to glycemic levels and food intake) and with the transition of responsibility for diabetes care from parents to adolescents, which may influence adolescents' diabetes outcomes and quality of life [6, 7].

Trying to explain the process of management of a chronic disease in daily family routines of adolescents and their families, Grey and colleagues [8] presented a Revised Framework of the Self and Family Management Model. This framework describes the complex processes implicated in the management of a chronic illness, such as T1D, and characterizes the main factors that influence patients' management with a chronic illness including the family [8]. According to these authors [8], the illness self-management process is a dynamic phenomenon that occurs in four dimensions. The first dimension is concerned with the facilitators and barriers describing the individual characteristics, the family context, and lifestyle, including community resources, the specificity of the health condition, and available health care resources [8, 9]. The second dimension, designated as self-management processes, describes how the individual and family focus on their illness needs, how they organize and activate the social resources to respond to their needs, and how the tasks and skills adopted and developed to manage illness needs are integrated into the individual's daily routines [10]. The third dimension called proximal outcomes describes the behaviors developed through the self-management process that allows patients and families to deal successfully with the symptoms and treatment of the disease [11]. Finally, the fourth dimension, known as distal outcomes, reveals the efficacy of all tasks and skills developed in the self-management process and includes the individual and family behaviors to cope with the disease often related to the use of health care services [8, 11]. The theoretical model recognizes that both self-management process factors and proximal outcomes may have a mediating effect between the facilitators/barriers dimension and the distal outcomes [8, 11].

Illness representations may influence adolescents' and their parents' response to self-management regarding an illness or their outcomes and may act as either facilitators or barriers [10]. In this study, both adolescents' and family's illness representations were considered since it is within the family environment that adolescents learn particular communication patterns, support, and health/illness representations [12]. Also, the dissimilarity between parents and adolescents regarding illness representations and the role that parents' illness representations may have in the adolescents' diabetes management process may influence adolescents' emotional and behavioral responses to diabetes management and contribute to family conflicts [13–15].

The literature showed that the representations of T1D consequences and emotional well-being in adolescents with T1D were related, with severity of diabetes illness representations being predictors of poorer well-being [15]. Also, Harvey and Lawson [16] found that less control beliefs over T1D were related to less adherence and poorer metabolic control. In turn, representations about treatment control were related to better well-being, social functioning, and metabolic control [17]. During adolescence, adolescents' representations related to personal or treatment control assume a special role because of the transferring process of diabetes management from parents to adolescents [12].

School support, an environmental factor considered by Grey and colleagues [8] and Schulman-Green and colleagues [10] as a facilitator or barrier factor, may negatively influence the individual and family management of diabetes. Sometimes, school staff does not have the sufficient knowledge and training to support adolescents with T1D, which may negatively influence their diabetes management and quality of life [18, 19]. In their study with university students with T1D, Balfe [20] found that the irregularities of daily schedules could take a toll on diabetes routines, mostly those regarding glycemic control, insulin administration, and dietary behavior. Additionally, diabetes self-care may negatively interfere with student practices, which may lead to the adoption of behaviors that are not favorable to diabetes management [20].

Family support and parental coping are some of the social factors that characterize the process dimension of Grey and colleague's framework [8]. The quality of family support has been associated with adherence, metabolic control, and quality of life [21–23]. In turn, when adolescents perceived family involvement as supportive, warm, caring, and cohesive, they felt more protected and safer, which positively influenced their quality of life [24, 25] and contributed to a better adaptation to T1D [26]. However, when adolescents perceived the parents' participation in diabetes tasks as negative parenting, characterized by controlling behaviors, nagging, and criticism, conflicts between both are more likely, which negatively influence the adolescent's quality of life, adherence, and metabolic control [27, 28]. Moreover, Jaser and Grey [27] noted that less supportive family environments with more conflicts were related with less adherence and, consequently, worse metabolic control. In turn, Harvey and Lawson [16] reported that in adolescents with T1D, social support and beliefs of diabetes severity were predictors of well-being.

Parental coping may influence the adaptation process to T1D in adolescents [8, 29] and have a mediating effect in the relationship between illness representations and adolescents' well-being [17], as postulated in Grey and colleague's framework [8]. Adherence behaviors are characterized as proximal outcomes and may play a mediating effect between process factors and distal outcomes [8]. Diabetes adherence is

compromised during adolescence [30] since adherence to diabetes tasks may conflict with the adolescents' developmental tasks (e.g., socialize with friends) [31]. Diabetes management may feel as an overwhelming task on the top of the other developmental tasks, adolescents have to deal with, what might explain why Miller and colleagues [32] found that teenagers between 13 and 17 years old showed bad metabolic control with HbA1c of 9.0%. In their study about the role of adherence in the relationship between family variables and metabolic control, Lewin and colleagues [33] concluded that adherence had a mediating effect on this relationship; i.e., a poor family support and functioning negatively influenced adherence behavior, which, in turn, contributed to poorer metabolic control. Therefore, the main aim of this study was to assess the adequacy of the Grey and colleagues' theoretical framework [8] in Portuguese adolescents with T1D and analyze the direct and indirect effects between illness representations (adolescents and family), parental coping, family support, and adherence, on metabolic control, quality of life and family functioning.

Methods

Procedures and Study Design

This study employed a cross-sectional design. Participants were selected for the study during a routine diabetes appointment. Data collection took place in two Portuguese hospitals: one pediatric hospital located in the south and one general hospital in the northern region. Both hospitals' ethical committees approved the study. After all participants had given their written informed consent, they were taken to a quieter room to answer the questionnaires. When both parents accompanied the adolescents, only the primary caregiver was invited to participate. The inclusion criteria were adolescents with T1D diagnosed for at least 1 year, aged between 12 and 19, and being followed in ambulatory regimen. Having another chronic illness besides T1D and using continuous glucose monitors or insulin pumps were exclusion criteria, because in both hospitals, adolescents were not using these diabetes devices since there is no co-payment from the government to acquire this equipment.

Participants

This sample included 100 adolescents with T1D and 100 parents. From the adolescents' sample, 52% were male and 48% female, with an average age of 15.12 years old (SD = 1.92). Regarding stage of adolescence, 24% were in early adolescence (aged between 12 and 13 years old), 47% in middle adolescence (aged between 14 and 16), and 29% in late adolescence (aged between 17 and 19), with 52% attending middle school. The mean age of diabetes onset was 8.50 years (SD = 3.57), and the mean duration was 6.60 years (SD = 3.77). From the total adolescents' sample, 88% of adolescents reported they checked their blood glucose and 90% administered insulin 4 or more times per day. Regarding parents, 78% of the mothers played the role of primary caregiver against the remaining fathers. Parents' mean age of 44.51 years old (SD = 5.66). As for education, 53% of parents had attended middle school, 25% had high school education, and 22% had higher education. From the total parents' sample, 87% were actively working, 73% lived in a traditional family (father, mother, child), and 77% reported having a good relationship with the extended family.

Instruments

Adolescents were assessed on school support, adherence to self-care, family support, and quality of life. Parents were assessed on parental coping and family functioning. Both adolescents and parents were assessed on illness representations.

Brief Illness Perception Questionnaire

Adolescents' and parents' illness representations were measured with the Brief-Illness Representations Questionnaire (Brief-IPQ) [34], which is based on the self-regulatory model of Leventhal and colleagues [35]. This instrument is composed of 9 items, each representing one dimension of the model (consequences, timeline, personal control, treatment control, identity, concern, coherence, emotional response, and causes). With the exception of the causal dimension, which is measured with an open-ended question asking participants to list the three most important causes of their illness, all other dimensions are answered on a 0-to-10-point scale [34]. In this study, as in other studies that used the Brief-IPQ, the causal dimension was not considered in either adolescents' or parents' illness representations [34, 36]. Parents answered regarding their perception of adolescent's T1D. Higher scores indicate a more threatening illness perception. The intercorrelations between each item in adolescents' and family's versions ranged between .201 and .639 and between .229 and .535, respectively.

School Support

The School Support Towards Diabetes Questionnaire (Pereira and Almeida 2009) assesses the perception of social support of friends, teachers, and school staff in adolescents with T1D regarding diabetes management during school activities. This scale is composed of 6 items scored on a 6-point scale. Higher scores indicate a higher perception of school support to manage self-care during school activities. In this study, the internal

consistency of the scale showed good psychometric properties with a Cronbach's alpha of .80.

Family Support

The Diabetes Family Behavior Scale is an instrument developed by McKelvey and colleagues [37] that measures the perception of children and adolescents regarding family support in their diabetes management. Both the global scale and the subscales guidance-control and warmth-caring showed good internal consistency with Cronbach's alphas of .86, .81, and .79, respectively [37]. The Portuguese version [38] showed similar Cronbach's alpha as the original version [37], i.e., .91 on the global scale and .76 and .81 in the subscales guidance-control and warmth-caring, respectively. Higher scores indicate lower family support. In this study, only the global scale was used, which showed good internal consistency with a Cronbach's alpha value of .83.

Parental Coping

Parental coping was measured with the Coping Health Inventory for Parents developed by McCubbin and colleagues [39]. This instrument asks parents with a child/adolescents with a chronic disease about the usefulness of different coping strategies in their daily routines, with answers ranging from 0 ("not helpful") to 3 ("extremely helpful"). It includes three domains: Maintaining family integration, cooperation, and an optimistic definition of the situation ($\alpha = .79$); maintaining social support, self-esteem, and psychological stability ($\alpha = .79$); and understanding the medical situation through communication with other parents and consultation with medical staff ($\alpha = .71$). In the Portuguese version [40], Cronbach's alpha for each subscale was .80, .82, and .76, respectively. Higher scores indicate better parental coping. In this study, the internal consistency of the subscales was maintaining family integration ($\alpha = .72$), maintaining social support ($\alpha = .81$), and understanding the medical situation ($\alpha = .71$).

Adherence

Adherence to self-care was measured using the Self Care Inventory-Revised [41]. The instrument is composed of 14 items asking the degree of adherence to self-care behaviors such as insulin intake, diet, exercise, and health care prevention in the previous month. Answers are given on a 5-point Likert scale where 1 represents "never" and 5 "always." Higher scores indicate better adherence to self-care. In this study, the global scale (Pereira and Almeida 2010) was used and showed a satisfactory internal consistency with a Cronbach's alpha of .73, slightly lower than the original version ($\alpha = .87$) [41].

Quality of Life

The Diabetes Quality of Life Questtionnaire [42] assesses quality of life in adolescents with T1D. The Portuguese version [43] is composed of 36 items organized into three subscales: Impact, Worries, and Satisfaction. Answers were given on a 5-point Likert scale, and either the original [42] or the Portuguese [43] version showed good internal consistency, with Cronbach's alpha in the overall global scale of .92 and .90, respectively. Higher scores indicate worse quality of life. In this study, only the overall global scale was used with good internal consistency, with a Cronbach's alpha of .92.

Family Assessment Device

The General Functioning subscale of the Family Assessment Device [44] was used to measure the overall family functioning. According to Miller and colleagues [45], this subscale represents the six dimensions of the McMaster Model of Family Functioning and measures the global family functioning. The Portuguese version of this subscale [46] is composed of 9 items answered in a 4-point Likert scale that ranged from strongly agree to strongly disagree. Higher scores indicate worse family functioning. In this study, the internal consistency was similar to the Portuguese version with a Cronbach's alpha of .79 slightly lower than the original version [44] that showed a Cronbach's alpha of .92.

Metabolic Control

Metabolic control was assessed using the adolescents' results of the glycosylated hemoglobin (HbA1c) recorded before the medical appointment that indicates the average of the glycemic levels of the previous 3 months [5]. To prevent short-term (hypoglycemia or hyperglycemia) and long-term (neuropathy, nephropathy, or retinopathy) diabetes complications, the International Society for Pediatric and Adolescent Diabetes (ISPAD) [5, 47] indicates that the HbA1c values in T1D must be lower than 7%. HbA1c higher than 9% represents a high risk of the development of diabetes complications [5]. Higher HbA1c results indicate worse metabolic control.

Data Analysis

To examine the relationship between adolescents' and family's illness representations, school support, family support, parental coping, adherence, metabolic control, quality of life, family functioning, and adolescent's age and gender, the Pearson and Spearman correlations were first performed and a path analysis was conducted, taking into account the Revised Self and Family Management Framework of Grey and colleagues [8] in adolescents with T1D. The exogenous variables were two: the facilitators and barrier variables of the

Grey and colleagues' framework [8], such as the adolescents' and family's illness representations and school support. Family support and parental coping, representing the self and family management process, and adherence to self-care considered a proximal outcome were treated as endogenous variables contributing to the indirect effect between the exogenous variables and the process and distal outcomes, respectively [8]. Metabolic control, adolescents' quality of life, and family functioning were the endogenous variables considered distal outcomes according to Grey and colleagues' model [8].

A sample of 200 is seen as a goal for SEM research [48]. However, a posteriori analysis was performed in order to assess the adequacy of the sample size to obtain a reasonable 0.8 level power. To perform this task, a Web-available macro from Preacher and Coffman [49] was used. Assuming a null hypothesis of close fit (H0: RMSEA = .00) and an alternative hypothesis of unacceptable fit (Ha: RMSEA = .10) [50], a significance level of alpha of .05 and 74 degrees of freedom, the Web procedure indicated that the minimum sample size required to achieve the desired level of 0.8 power was 50 participants.

Data was analyzed with the SPSS AMOS version 23 (IBM Corporation, Armonk, NY, USA). To assess the adequacy of the model fit, the chi-square test (χ^2), the comparative fit index (CFI), the Tucker-Lewis index (TLI), the root mean square error approximation (RMSEA), and the standardized root mean square residual (SRMR) were used as Brown [51] indicated, and the Akaike information criterion (AIC) and the Bayesian information criterion (BIC) as Ferron and colleagues [52] suggested. The indirect paths were tested with 5000 bootstrap samples and a 95% confidence interval (CI) [53].

Results

The correlations between all variables are presented in Table 1. The results of the final model showed nonsignificant χ^2, CFI, and TLI higher than .95, a RMSEA value smaller than .06, and a SRMR value smaller than .08. Also, the final model showed that the AIC and BIC indexes decrease considerably [52]. Therefore, the final model revealed a good fit to the data [51, 52] explaining 31% of the variance in metabolic control, 40% in quality of life, and 19% in family functioning.

Effects of Adolescents' and Family's Representations on Quality of Life, Family Functioning, and Metabolic Control

More threatening adolescents' perceptions of diabetes consequences and emotional representation were associated with lower quality of life. Also, perceptions of less treatment control and more illness concerns were associated with worse family functioning. More threatening emotional representations, in adolescents, and higher perceptions of consequences, in parents, were associated with worse metabolic control (high glycemic levels) (see Fig. 1).

Adolescents' illness representations (identity and coherence), the family's illness representations (timeline, control through treatment, identity, coherence, and emotional response), and school support did not show a significant association with any constructs of Grey and colleagues' framework [8].

Effect of Parental Coping in the Association Between Adolescents' Timeline Representations, Family's Concerns Representations, and Metabolic Control

The analysis of the indirect effect showed that only Family Concerns Illness representations → Parental Coping (Comprehension of Medical Situation) → Metabolic Control had a significant indirect effect (Table 2).

Effect of Family Support and Adherence in the Association Between Adolescents' Personal Control Representations, Family's Concerns Representations, and Quality of Life/Family Functioning/Metabolic Control

The results showed a significant indirect path to family functioning: Adolescents' Personal Control Illness representations → Family Support → Family Functioning. Regarding quality of life, the analysis showed two significant indirect paths: Adolescents' Personal Control Illness representations → Family Support → Quality of Life and Family's Concerns Illness representations → Family Support → Quality of Life. Also, Adolescents' Personal Control Illness representations → Family Support → Adherence → Metabolic Control, and Family's Concerns Illness representations → Family Support → Adherence → Metabolic Control showed an indirect path (Table 2).

Effect of Adherence in the Association Between Adolescent's and Family's Personal Control Representations and Metabolic Control

The results showed that Adolescents' Personal Control Illness representations → Adherence → Metabolic Control and Family's Personal Control Illness representations → Adherence → Metabolic Control were significant indirect paths (Table 2).

The indirect pathway to family functioning through family's illness representations (concerns) (Family Concerns Illness representations → Family Support → Family Functioning) and to metabolic control through adolescents' illness representations (Adolescent's Timeline Illness

Table 1 Correlations for study variables ($N = 100$ Portuguese adolescents with T1D + 100 parents)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14
IPQ Consequences Adol.	--													
IPQ Timeline Adol.	.114													
IPQ Pers. Control Adol.	.333***	.111												
IPQ Treat. Control Adol.	−.022	.180	−390***											
IPQ Identity Adol.	.184	.020	.037	.074										
IPQ Concerns Adol.	.261**	.151	−.148	−.160	.128									
IPQ Coherence Adol.	.457***	.161	.539***	.246*	−.036	−.104								
IPQ Emotional Repr. Adol.	.639***	.118	.408***	.049	.201*	.173	.393***							
IPQ Consequences Par.	.439***	.094	.261**	.059	.067	.046	.254*	.365***						
IPQ Timeline Par.	.084	.204*	.083	−.005	.096	.062	−.004	.189	.134					
IPQ Pers. Control Par.	.159	.269**	.407***	.161	.128	.002	.239*	.270**	.297**	.016				
IPQ Treat. Control Par.	.045	−.044	.111	−.050	.145	−.052	−.074	.140	.116	−.021	.116			
IPQ Identity Par.	.061	−.081	.079	−.056	.048	−.142	.058	−.002	.229*	.130	.027	−.028		
IPQ Concerns Par.	.139	−.031	.017	.020	−.131	.093	−.036	.096	−.087	.062	−.247*	−.046	.103	
IPQ Coherence Part.	.085	.298**	.119	.082	.041	.070	.197*	.072	.299**	−.088	.521***	.012	.024	−.382***
IPQ Emotional Repr. Par.	.395***	.052	.072	−.148	.128	.250*	.239*	.416***	.535***	.007	.181	.013	.246*	.007
School Support	−.009	.060	−.202*	−.158	.022	−.016	−.034	−.029	−.069	−.154	−.142	.000	−.211*	.056
Family Support	−.048	.091	−.365***	−.143	.043	.222*	−.218*	−.130	−.107	.126	−.119	−.145	−.171	.199*
Parental Coping (Maint. Family Integration)	.033	.129	−.045	−.062	.067	.079	.033	.073	−.067	−.009	−.202*	−.200*	−.030	.189
Parental Coping (Maint. Family Support)	.108	.101	−.153	−.009	.074	.094	.018	.195	.001	.151	−.210*	−.035	−.055	.167
Parental Coping (Underst. Medical Situation)	−.036	.206*	−.103	.060	.071	.058	.016	.138	−.011	.089	−.125	−.072	.001	.212*
Adherence	−.219*	−.067	−.506***	−.134	−.008	.189	−.369***	−.187	−.145	.083	−.373***	−.075	−.124	.106
Quality of Life	.153***	.136	.375***	.016	.202*	.154	.314***	.544***	.358***	.123	.252*	.049	.179	.001
Metabolic Control	.296**	.042	.406***	.003	.107	.072	.329***	.362***	.339***	.055	.273**	.025	.015	−.150
Family Functioning	.233*	.035	.229*	.250*	.022	.092	.249*	.228*	.116	.018	.135	.114	−.037	−.106
Adolescent Age	.098	−.201*	.034	−.119	.147	.036	.024	−.012	−.137	−.130	−.064	.212*	.016	−.040
Adolescent Gender	−.211*	−.235*	−.244*	−.063	.071	−.245*	−.033	−.232*	−.252*	−.037	−.073	−.186	−.048	−.040

Variables	15	16	17	18	19	20	21	22	23	24	25	26
IPQ Consequences Adol.												
IPQ Timeline Adol.												
IPQ Pers. Control Adol.												
IPQ Treat. Control Adol.												
IPQ Identity Adol.												
IPQ Concerns Adol.												
IPQ Coherence Adol.												
IPQ Emotional Repr. Adol.												
IPQ Consequences Par.												
IPQ Timeline Par.												
IPQ Pers. Control Par.												
IPQ Treat. Control Par.												
IPQ Identity Par.												
IPQ Concerns Par.												
IPQ Coherence Part.												
IPQ Emotional Repr. Par.	.237*											
School Support	−.120	.036										

Table 1 (continued)

Family Support	−.152	−.120	.362***												
Parental Coping (Maint. Family Integration)	−.033	.029	.060	.117											
Parental Coping (Maint. Family Support)	.018	.034	.180	.164	.599***										
Parental Coping (Underst. Medical Situation)	−.108	.018	.145	.083	.364***	.432***									
Adherence	−.225*	−.115	.273**	.527***	.009	.119	.132								
Quality of Life	.168	.326***	−.400***	−.296**	−.058	−.055	−.064	−.273**							
Metabolic Control	.206*	.345***	−.215*	−.255*	.013	−.024	−.232*	−.35***8	.355***						
Family Functioning	.116	.171	.009	−.277**	−.056	.037	−.012	−.232*	.197*	.143					
Adolescent Age	−.043	.044	.051	−.235*	−.177	−.055	.125	−.097	−.020	−.120	−.008				
Adolescent Gender	−.054	−.131	−.044	.136	.015	.035	.076	.001	−.137	−.137	−.149	−.026			

IPQ illness perceptions representations, *Adol.* adolescents, *Par.* parents

*$p < .05$; **$p < .01$; ***$p < .001$

representations → Parental Coping (Comprehension of Medical Situation) → Metabolic Control) were not significant.

Discussion

This study assessed the adequacy of the Grey and colleagues' theoretical framework [8] in Portuguese adolescents with T1D and the indirect effects of parental coping, family support, and adherence in the association between adolescents'/family's illness representations and metabolic control, quality of life, and family functioning. The results showed a direct effect between adolescents' and parents' illness representations and quality of life, metabolic control, and family functioning. Thus, more consequences and worse emotional response to T1D were associated with worse quality of life. These results are consistent with the literature [15, 17] that has shown a more negative impact and consequences of illness representations were related to less well-being, contributing to anxiety and depressive symptoms in the adolescent. Also, less treatment control and more concerns of adolescents' diabetes representations were related to worse family functioning and more emotional representations were associated with worse quality of life and worse metabolic control (higher glycemic values). In turn, more family consequences representations were related to worse metabolic control (higher glycemic values). Thus, negative representations regarding self-management processes such as perceiving that diabetes treatment does not allow an effective control and management of the disease but rather requires difficult, hard, and time-consuming tasks have a negative influence in the self-management process [10]. Adolescents' performance with T1D management is one of the most important factors that can create and explain conflicts with parents regarding the management of T1D [28, 54], with parents assuming either an overprotective behavior, not recognizing adolescent's ability and independence to manage their diabetes [55], or adolescents perceive parents' participation in diabetes management as intrusive and controlling [14]. Moreover, Skinner and colleagues [56] found that adolescents' illness representations regarding diabetes impact and treatment's effectiveness were related to dietary self-care management and the absence of a relationship between adolescents' illness representations and glycemic control was explained by the close involvement of parents that took responsibility over that particular self-care behavior removing adolescent's responsibility.

In the analysis of the indirect effect of parental coping, this study found that more parents' concerns with adolescents' diabetes were related to better parental coping, which, in turn, was associated with better metabolic control. Also, family support had an indirect effect on the relationship between

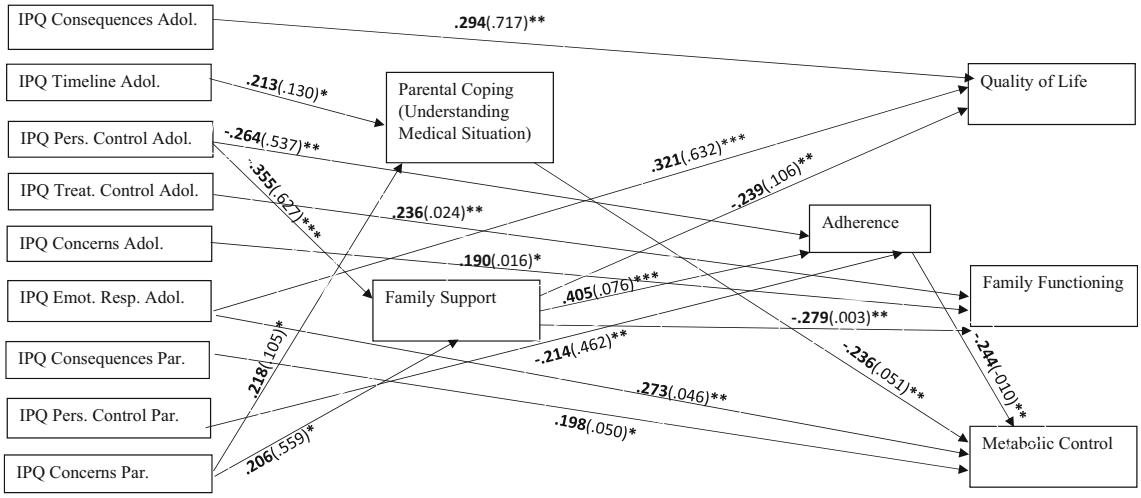

Fig. 1 Path analysis of Portuguese adolescents with T1D and family associated with adherence, metabolic control, quality of life, and family functioning ($N = 100$ Portuguese adolescents with T1D + 100 parents). IPQ illness perceptions representations, Adol. adolescents, Par. parents. Only significant pathways are represented with coefficients (standard error) in bold. Model fits: $\chi^2(74) = 66.310$; $p = .726$; RMSEA = .000 (CI .000, .045); TLI = 1.036; CFI = 1.000; SRMR = .077; $*p < .05$; $**p < .01$; $***p < .001$

adolescents' personal control and family functioning. Grey and colleagues' framework [8] postulates that the process factors, such as parental coping and family support, may have a mediating effect between illness representations and metabolic control/family functioning. Additionally, the study of Edgar and Skinner [17] found that illness representations of adolescents with T1D were related to coping although the latter did not act as a mediator in the relationship between illness representations and well-being. In turn, the implications of daily diabetes management may influence family functioning and compromise the diabetes adaptation process of adolescents and their families. Nonetheless, in the study of Knafl and colleagues [57] regarding the relationship between family's patterns to manage a chronic condition in children and their relationship with family functioning, the results showed that the majority of families had integrate and successfully managed illness demands in their family's daily activities without a negative impact in family functioning or in the adaptation process of all members involved.

Adherence also showed an indirect effect on the relationship between adolescents' and family's personal control representations and metabolic control. Also, Grey and colleagues [8] and Ryan and Sawin [11] concluded that adherence to self-management represents a proximal outcome resulting from the adolescents' and family's abilities to manage diabetes demands in daily life routines. Lewin and colleagues [33] studied the role of adherence in the relationship between family variables and diabetes outcomes, especially metabolic control, in adolescents and concluded that adherence had a mediating effect on these relationships.

This study also found that the adolescents' personal control representations and parents' concerns representations were related to family support, which was associated with adherence and, consequently, was related to metabolic control. These findings are confirmed by the main postulates of the self and family management model [8], in which the process factors (family support and parental coping) and proximal outcomes (adherence to self-care) may have an indirect effect between illness representations and metabolic control, quality of life, and family functioning. Additionally, Edgar and Skinner [17] showed, in their study regarding the relationship between illness representations and family variables in adolescents with T1D, how illness representations were related to family variables, with the latter being mediators in the relationship between personal beliefs and psychosocial outcomes, such as well-being. Based on the findings of the present study, the Grey and colleagues' theoretical framework [8] behaved adequately in Portuguese adolescents with T1D.

Implications for Practice

This study shows how illness representations of adolescents and their families may influence the process of diabetes management, which may compromise specific diabetes outcomes, such as adherence, metabolic control, and quality of life, and how family dynamics are affected. The present findings also reveal the importance of knowing and characterizing illness representations in adolescents with T1D and their families, and particularly, the degree of similarity or dissimilarity since conflicts may arise between them. Intervention programs that try to develop a collaborative work between parents and adolescents may contribute to similar illness representations and less family conflicts and facilitate the diabetes shared management [14]. The identification of dissimilarity in illness representations between parents and adolescents also allows to anticipate the family's diabetes management patterns and

Table 2 Significant indirect effects and goodness-of-fit indexes (standardized solution: N = 100 Portuguese adolescents + 100 parents)

Predictor		Indirect effect		Outcome	β	SE	95% CI (LL, HL)
IPQ Pers. Control Adol.	→	Family support	→	Family functioning	*.098*	.043	*.032, .193*
IPQ Pers. Control Adol.	→	Family support	→	Quality of life	*.779*	.045	*.174, 1.946*
IPQ Pers. Control Adol.	→	Family support → Adherence	→	Metabolic control	*.053*	.051	*.012, .126*
IPQ Pers. Control Adol.	→	Adherence	→	Metabolic control	*.139*	.049	*.039, .267*
IPQ Concerns Par.	→	Parental coping (Underst. Med. Sit.)	→	Metabolic control	*− .070*	.032	*− .152, − .022*
IPQ Concerns Par.	→	Family support → Adherence	→	Metabolic control	*− .030*	.021	*− .087, − .001*
IPQ Pers. Control Par.	→	Adherence	→	Metabolic control	*.106*	.029	*.034, .212*

	χ^2	df	p	RMSEA	p	90% CI	CFI	TLI	AIC	BIC
Model 1 (original model)	97.555	28	*.000*	.158	*.000*	.125, .193	.871	− .379	691.555	1465.291
Model 2 (final model)	66.31	74	.726	*.000*	.970	.000, .045	1.000	1.036	158.310	278.148

Coefficients styled in italics and 95% CI were significant

SE standard error, *CI* confidence interval, *LL* lower limit, *HL* higher limit, *IPQ* illness perceptions representations, *Adol.* adolescents, *Par.* parents, χ^2 chi-square, *df* degrees of freedom, *RMSEA* root mean square error for approximation, *CFI* comparative fit index, *TLI* Tucker-Lewis index, *AIC* Akaike information criterion, *BIC* Bayes information criterion

Reference values: RMSEA < .05 good fit, .05–.08 adequate fit, >.10 poor fit; CFI/TLI > .95 good fit

intervene to prevent no adherence and diabetes complications. As Edgar and Skinner [17] had concluded, health professionals must avoid organize their intervention programs around diabetes complications to try to improve adolescent's adherence, because this may be a counterproductive measure, since adolescent's illness representations related with diabetes outcomes are short-term. The reciprocity between the constructs is recognized in the revised self and family management framework [8] and may suggest a longitudinal feedback loop that could be both helpful and harmful to long-term outcomes in adolescents with T1D.

Due to the number of hours that adolescents spend in school activities, it is crucial that intervention programs join teachers, school staff, and peers involved in the diabetes self-management process to improve their knowledge about diabetes and its self-care and to provide the right conditions to allow self-care tasks without interrupting school activities, which may negatively influence adolescents' adherence behaviors. To decrease the difficulties that T1D adolescents have during school activities, health professionals need to know adolescents' difficulties [20] and create partnerships with teachers, school staff, and peers to improve adolescents' diabetes management during school activities. Also, intervention programs to improve family support and coping should be implemented, with the aim of developing better family communication patterns and problem-solving skills to minimize conflicts between parents and adolescents and to improve the diabetes self-management process. To increase the transference of responsibility from parents to adolescents and the successful sharing of diabetes self-care, it is important that health professionals help adolescents and parents recognize the independence and autonomy level of adolescents in diabetes management, to prevent conflicts and promote adolescent's self-care behaviors. To improve diabetes management and prevent their complications and family conflicts, Schilling and colleagues [58] concluded that it is important that health professional improve their knowledge about the patterns and responsibilities involved in the shared management between adolescents and families and provided adequate targeted assistance.

Limitations

The most important limitation of this study is the convenience sample and the cross-sectional design, which imposes some cautions in the inference of causal relationships between variables and not allow to temporal precedence to be mapped as the Grey and colleagues' model preconized [8]. The reliance on self-report measures is also a limitation, in which adolescents may over-report their self-care behaviors, which may explain the discrepancies between their self-care levels and their glycemic values, which are considered a high risk of the development of diabetes complications [5].

Future studies should use a prospective design and analyze the changes in the self-management process of adolescents and families over time and how different proximal outcomes, such as self-care adherence, may contribute to improve the self-management process and, consequently, the distal outcomes [11]. Also, the shared management of diabetes between adolescents and parents should be assessed to better understand the changes during adolescents and how they may influence diabetes outcomes and family interactions.

Conclusions

In this study, illness representations of adolescents with T1D and of their families and family variables interact and influence the diabetes management process, diabetes outcomes, and family functioning, as the Grey and colleagues [8] postulated. Family support and adherence play an important role associated to relationships between illness representations of adolescents and families and metabolic control. Family variables, such as parental coping and family support had an indirect effect on the relationship between adolescents'/families' illness representations and metabolic control/family functioning. Only adolescents' and family's illness representations were associated with adolescents' quality of life. Grey and colleague's framework [8] allows the recognition of how individual and family factors may interfere with illness management process, which may contribute to improve health care practices and the relationship between health care professionals and individual/families with a chronic illness.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The ethical committee of the hospital where data was collected (Central Lisbon University Hospital Centre Process no. 68-CHLC) approved the study.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Welfare of Animals This paper does not contain any studies with animals performed by any of the authors.

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