

Family functioning and quality of life in adolescents with type 1 diabetes: The role of dissimilarity in illness representations and school support

*Clinical Child Psychology
and Psychiatry*

2020, Vol. 25(2) 494–506

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DOI: 10.1177/1359104519895054

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Abstract

This study analyzed the impact of dissimilarities in illness perceptions between parents and adolescents, school support, and family functioning on quality of life of adolescents with type 1 diabetes (T1D). A total of 100 adolescents diagnosed with T1D for at least 1 year and a primary caregiver participated in the study (N=200). Adolescents answered the Diabetes Quality of Life and the School Support Questionnaire, and parents answered the general functioning subscale of the Family Assessment Device. Both answered the Brief-Illness Perception Questionnaire, regarding the adolescents' diabetes. The interception effect of dissimilarities regarding identity and concerns perceptions toward diabetes, between parents and adolescents, and school support in the relationship between family functioning and quality of life was significant and explained 27% and 32% of the variance, respectively. The results showed a negative relationship between family functioning and quality of life when school support was low and dissimilarities in identity and concerns perceptions were high. Therefore, to increase quality of life of adolescents with T1D, intervention programs should include family, teachers, school staff, and peers to improve their knowledge of diabetes and support to adolescents.

Keywords

QoL, family functioning, school support, dissimilarity in illness perceptions, type 1 diabetes, adolescents

Introduction

Type 1 diabetes (T1D) is one of the most frequent chronic disease in adolescents and, in Portugal, its prevalence is about 3327 cases in individuals aged between 0 and 19 years in 2015 (Portuguese Society of Diabetology, 2016). The self-care of T1D requires a balance between different behaviors

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that occur during daily activities, such as monitoring glycemic levels and administering insulin injections several times per day, counting carbohydrates in all meals, and engaging in physical activity (Rewers et al., 2014). Diabetes self-care maintains normal glycemic values preventing future diabetes complications (Donaghue et al., 2018). During adolescence, metabolic control and quality of life (QoL) decrease, but diabetes knowledge, skills, and responsibility grow progressively with the adolescent's maturity and cognitive development (Grecco et al., 2001).

As Grey et al. (2015) suggested in their model about the self- and family-management process in chronic illness, both personal factors, such as beliefs regarding diabetes, and the social context that includes parents, friends, and teachers, influence family functioning and adolescent's QoL (Anderson, 2003; Wagner et al., 2006; Wysocki & Greco, 2006).

The adolescents' process of development of illness perceptions is greatly influenced by their family environment and health/illness personal experiences (Skinner & Hampson, 2001). In adolescence with T1D, these beliefs will change either with daily diabetes experiences or with the transferring of responsibility for diabetes tasks from parents to adolescents (Skinner & Hampson, 2001). Thus, with the decreased egocentrism and the acquisition of better cognitive abilities to perform diabetes tasks during adolescence, adolescents' illness perceptions become more realistic and more like their parents' perceptions, although there is no significant improvement in diabetes outcomes even in older adolescents (Butner et al., 2009; Skinner & Hampson, 2001).

Regarding the dissimilarities in illness perceptions between parents and adolescents, Law (2002) and Olsen et al. (2008) concluded that the degree of consistency between parents and adolescents was high, except regarding the consequences and emotional perceptions, with mothers perceiving diabetes with worse consequences and, therefore, more negative than adolescents. Although Law (2002) and Olsen et al. (2008) studies were the only ones that have attempted to analyze the relationship in dissimilarity regarding illness perceptions between parents and adolescents on the psychological well-being of adolescents with T1D, neither study found a significant relationship.

Nonetheless, the presence of dissimilarities in illness perceptions between parents and adolescents may be interpreted as a normative developmental process that may contribute to change the parental relationship regarding diabetes self-care management and the beginning process of negotiating the adolescent's autonomy and independence in diabetes care tasks (Miller & Drotar, 2003). The optimistic illness perceptions of younger adolescents may reinforce mothers' threatening beliefs regarding diabetes impact, contributing to an overwhelming protection, with the consequent loss of adolescent's control and responsibility in diabetes management (Gaston et al., 2011). In turn, older adolescents may be more successful in dealing with diabetes tasks, as they become more independent from parents, which may explain the lower discrepancies in family perception about adolescents' diabetes performance (Butner et al., 2009) and the contribution of adolescents' diabetes beliefs to their QoL (Law, 2002; Skinner & Hampson, 2001). Also, the process of transferring the responsibility of diabetes management from parents to adolescents is influenced by developmental and psychosocial factors such as the skills of parents and adolescents to deal with diabetes that may create family conflicts resulting in burnout derived from the complex and daily self-care management of diabetes tasks and the constant negotiation of family involvement to guarantee the adolescent achieves an optimal glycemic control and psychological well-being (Butler & Lawlor, 2004; Guo et al., 2011). Less positive and supportive parental strategies contribute not only to more family conflicts and worse diabetes outcomes (Almeida et al., 2015; Duke et al., 2008; Skinner et al., 2000), but negatively impact parents' perceptions about adolescents' responsibility and competence in diabetes care management (Fogel & Weissberg-Benchell, 2010; Moore et al., 2013).

The management of diabetes self-care occurs in all daily adolescents' activities, and because of the organization and scheduling of school activities, adolescents with T1D may have more

difficulties in developing and managing diabetes self-care tasks (Butler & Lawlor, 2004; Miller & Drotar, 2003; Wagner et al., 2006). Thus, participation in school activities may negatively influence adolescent's QoL (Pansier & Schulz, 2015). Also, insufficient knowledge and training of teachers and school staff may negatively influence adolescents' QoL and be related to a less supportive environment, increased diabetic complications, and feelings of teasing and alienation from healthy peers (Mandali & Gordon, 2009; Wagner & James, 2006). When school staff and peers were given adequate training to improve their knowledge about diabetes management and how to help adolescents performing diabetes tasks during their school activities, adolescents' QoL improved (Butler & Lawlor, 2004; Nabors et al., 2005).

This study analyzed the relationship between dissimilarities in illness perceptions, school support, family functioning and QoL, and the effect of school support and dissimilarities in illness perceptions between parents and adolescents with T1D, in the relationship between family functioning and QoL. It was hypothesized that (1) more dissimilarities in illness perceptions, lower school support, and worse family functioning would be associated with worse QoL and (2) more dissimilarities in illness perceptions between parents and adolescents and lower school support would moderate the negative relationship between family functioning and QoL.

Methodology

Study design and sample

The sample included 200 participants: 100 adolescents with T1D and 100 primary caregivers. This study followed a cross-sectional design and used a convenience sample. Participants were contacted in a pediatric diabetes unit in two Portuguese urban hospitals. Adolescents were diagnosed with T1D according to the International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines (Rewers et al., 2014). The inclusion criteria for this study included: T1D diagnosis for at least 1 year, participants aged between 12 and 19 years and accompanied by a parent. Having another chronic disease, a neurocognitive disorder, or not being in an ambulatory regimen were the exclusion criteria.

The sample included 52 male and 48 female adolescents with a mean age of 15.12 years ($SD=1.9$; middle adolescence), a mean of diabetes duration of 6.6 years ($SD=3.77$), and a mean age of 8.5 years ($SD=3.5$) when diagnosed with diabetes. The glycated hemoglobin averaged 9.1% ($SD=1.61$), which is classified by ISPAD guidelines (Rewers et al., 2014) as a high risk for the appearance of diabetes complications. At least 35% of adolescents were in middle school and 63% in high school. In total, 78% of adolescents had their mothers as primary caregivers with a mean age of 44.51 years ($SD=5.66$). A total of 71% of primary caregivers worked full-time, 22% had finished middle school, and 25% had finished high school.

Procedure

The study's protocol and design were approved by the ethical committees of both hospitals (Process no. 68-CHLC), and all adolescents and parents participated voluntarily and anonymously. All participants that met the inclusion criteria were invited by the adolescent's physician and signed an informed consent. Less than 3% of parents declined to participate and the main reason provided was the time required to complete the questionnaires. Adolescents and parents answered the instruments, provided by the researchers, in a quiet room in the hospital after the medical appointment. When both parents accompanied the adolescent to the medical appointment, only the adolescents' primary caregiver participated in the study.

Measures

Adolescents answered the Diabetes Quality of Life (Ingersoll & Marrero, 1991) and the School Support Questionnaire (Pereira & Almeida, 2009) whereas parents answered the General Functioning subscale of the Family Assessment Device (Ryan et al., 2005). Both parents and adolescents answered the Brief-Illness Perception Questionnaire (Brief-IPQ; Broadbent et al., 2006).

Diabetes QoL. The QoL of adolescents was measured using the validated Portuguese version (Almeida & Pereira, 2008) of Ingersoll and Marrero's (1991) Diabetes QoL for Youths. The instrument is composed of 36 items organized into three subscales: diabetes impact, satisfaction with treatment and life, and worries about the future. Answers are scored on a 5-point Likert-type scale ranging from 1 (never) to 5 (always), with higher scores indicating worse QoL. In this study, only the total scale was used, which had an internal consistency coefficient of .92, similar to the Portuguese version with adolescents with T1D ($\alpha = .92$; Almeida & Pereira, 2008).

School support in T1D. This instrument assesses the adolescents perception of school support in the management of self-care during school activities (Pereira & Almeida, 2009). The instrument is composed of six dimensions that assess the support of teachers, friends, and school staff in the management of diabetes during daily school activities. Each item includes a sentence about the perception of school support that adolescents rate on a 6-point Likert scale from 1 (low school support) to 6 (high school support). High scores indicate a high perception of school support. The total score used in this study showed a Cronbach' alpha of .80.

Family functioning. This study used the Portuguese version of the General Functioning subscale adapted in Portuguese families with adolescents with T1D and healthy adolescents (Almeida et al., in press), which is considered a brief measure of the overall family functioning (Ryan et al., 2005; Miller et al., 2000). The subscale is composed of nine items that describe different situations of family functioning, where the participant is asked to rate how well the sentences describe their family (strongly agree, agree, disagree, and strongly disagree). Higher scores indicate worse family functioning. In this study, the general functioning subscale showed good internal consistency ($\alpha = .79$), similar to the sample of Portuguese parents of adolescents with T1D ($\alpha = .79$) and slightly lower than the sample of Portuguese parents of healthy adolescents ($\alpha = .84$) (Almeida et al., in press).

Illness Perceptions. Both adolescents with T1D and their parents completed the Brief-IPQ (Broadbent et al., 2006; Figueiras et al., 2009). Parents answered the questionnaire taking into consideration their perception of the adolescent's diabetes. This instrument is composed of nine subscales of illness representations: consequences (implications of the illness), timeline (duration of the illness), personal control (personal skills to control the illness), treatment control (perception of efficacy of the treatment to control the illness), identity (labels regarding the illness and its symptoms), concern (preoccupations related with the illness), coherence (degree of understanding of the illness), emotional representation (regarding the emotional component of the illness), and causal factors (Broadbent et al., 2015; Leventhal et al., 2003). Only the first eight subscales of illness representations were used and were rated within a 0–10 Likert scale (Broadbent et al., 2006).

The dissimilarity in illness perceptions between parents and adolescents was calculated by the method indicated by Olsen et al. (2008). Low scores indicate greater similarity between both participants, whereas higher scores show greater dissimilarity between parents and adolescents' illness perceptions.

Data analyses

Descriptive statistics and Pearson Correlations were calculated to analyze the relationships between the family general functioning, school support, and dissimilarities in illness perceptions between parents and adolescents, with QoL, as stated by hypothesis 1.

The dissimilarity in each one of the eight illness representation was calculated through the sum of the squared differences of each item, as Olsen et al. (2008) have proposed. Then, to test hypothesis 2 and to estimate the effects of dissimilarity in illness perceptions, between parents and adolescents, and school support in the relationship between family functioning and QoL, several moderated moderation models (three-way interaction) (Dawson, 2014) were performed using macro Process for SPSS (model 3) (Hayes & Preacher, 2013). Eight models, one for each subscale of dissimilarities in illness perceptions, were tested using a bootstrapping technique and 95% bias-corrected confidence intervals were determined, being significant when zero was not included in the interval (Hayes & Preacher, 2013) and either the two-way interactions or the three-way interaction being significant. On all models tested, diabetes duration was included as a covariate variable to control for potential confounding effects.

Results

Relationship of general functioning, dissimilarity in illness perceptions, and school support with QoL

School support ($r = -.400$; $p < .001$) and dissimilarities in illness representations (emotional representation) ($r = -.205$; $p < .05$) were negatively associated with QoL and general functioning was positively related with QoL ($r = .197$; $p < .05$).

The effect of dissimilarities in illness representations and school support

The interaction between the General Functioning subscale, Dissimilarity in Identity, and School Support was significant ($b = -0.101$; $SE = 0.044$; $t = -2.279$; $p < .05$; lower limit of the 95% confidence interval (LL 95% CI) = -0.189 ; upper limit of the 95% confidence interval (UL 95% CI) = -0.013), which confirmed the hypothesis. This model explained 27.16% of the variance on adolescents' QoL ($F(8, 91) = 4.241$; $p < .001$). Only when school support was lower was the interaction effect of dissimilarity in identity on family functioning significant ($b = 0.785$; $SE = 0.381$; $t = 2.062$; $p < .05$; LL 95% CI = 0.029 ; UL 95% CI = 1.541). In the model, diabetes duration was not significant ($b = -0.471$; $SE = 0.489$; $t = -0.962$; $p > .05$; LL 95% CI = -1.443 ; UL 95% CI = 0.501). Thus, a negative relationship was found between family functioning and QoL when school support was lower and dissimilarity in identity between parents and adolescents was higher ($b = 15.048$; $SE = 7.227$; $t = 2.082$; $p < .05$; LL 95% CI = 0.693 ; UL 95% CI = 29.403) (see Figures 1 and 2).

The hypothesis stating that dissimilarity regarding concerns about diabetes between parents and adolescents and school support were moderators in the relationship between family functioning and QoL was confirmed ($b = -0.102$; $SE = 0.034$; $t = -3.014$; $p < .01$; LL 95% CI = -0.170 ; UL 95% CI = -0.035). This model explained 32.10% of the variance on QoL ($F(8, 91) = 5.377$; $p < .001$). The interaction between family functioning and dissimilarity regarding concerns toward diabetes was moderated by lower school support ($b = 1.126$; $SE = 0.366$; $t = 3.080$; $p < .01$; LL 95% CI = 0.400 ; UL 95% CI = 1.852). In the model, diabetes duration was not significant ($b = -0.640$; $SE = 0.470$; $t = -1.362$; $p > .05$; LL 95% CI = -1.574 ; UL 95% CI = 0.294). Thus, a negative relationship was found between family functioning and QoL when school support was lower and dissimilarity in concerns between parents and adolescents was higher ($b = 24.559$; $SE = 8.191$; $t = 2.998$; $p < .01$; LL 95% CI = 8.288 ; UL 95% CI = 40.830) (see Figures 3 and 4).

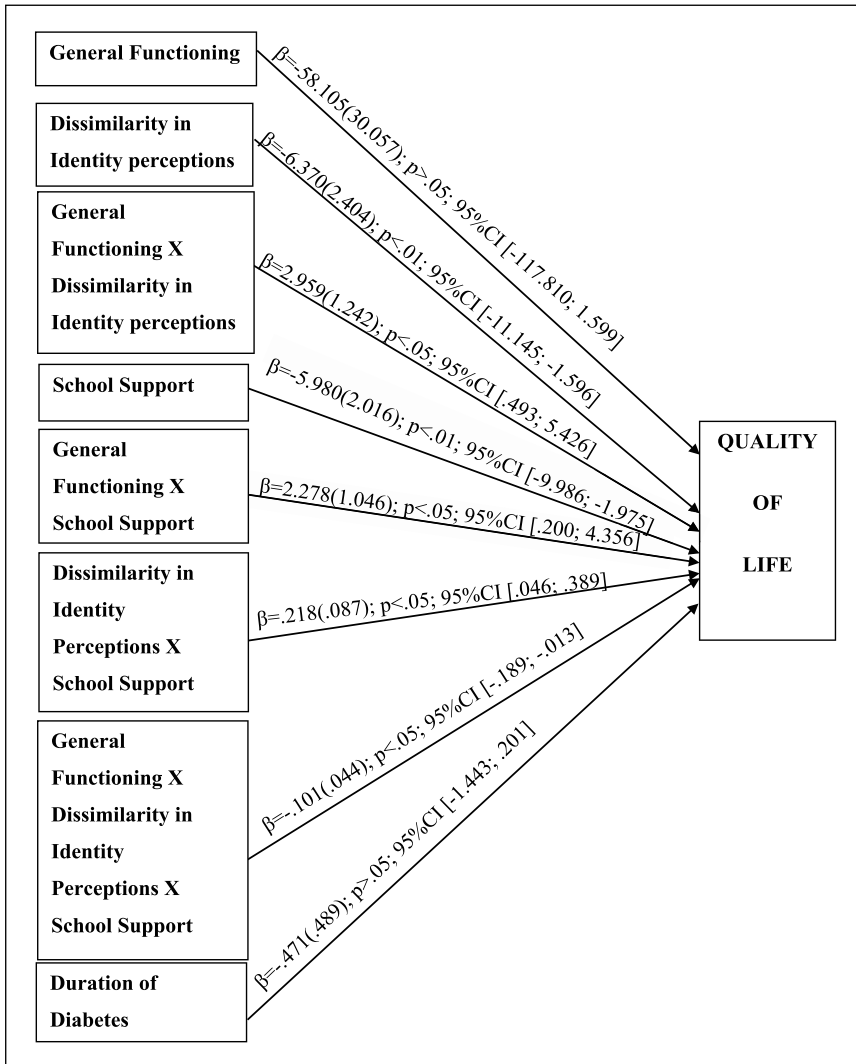


Figure 1. Dissimilarity in identity perceptions between parents and adolescents, and school support as moderators in the relationship between family functioning (general functioning) and QoL. β (standard error); 95% CI (lower limit of 95% confidence interval (LL 95% CI); upper limit of 95% confidence interval (UL 95% CI)).

The models, that tested if the remaining dissimilarities in illness perceptions between parents and adolescents with school support were moderators in the relationship between family functioning and QoL, were not significant.

Discussion

This study analyzed the association between dissimilarity in illness representations, school support, and family functioning with QoL, and the effect of school support and dissimilarities in illness perceptions between parents and adolescents in the relationship between family functioning and QoL.

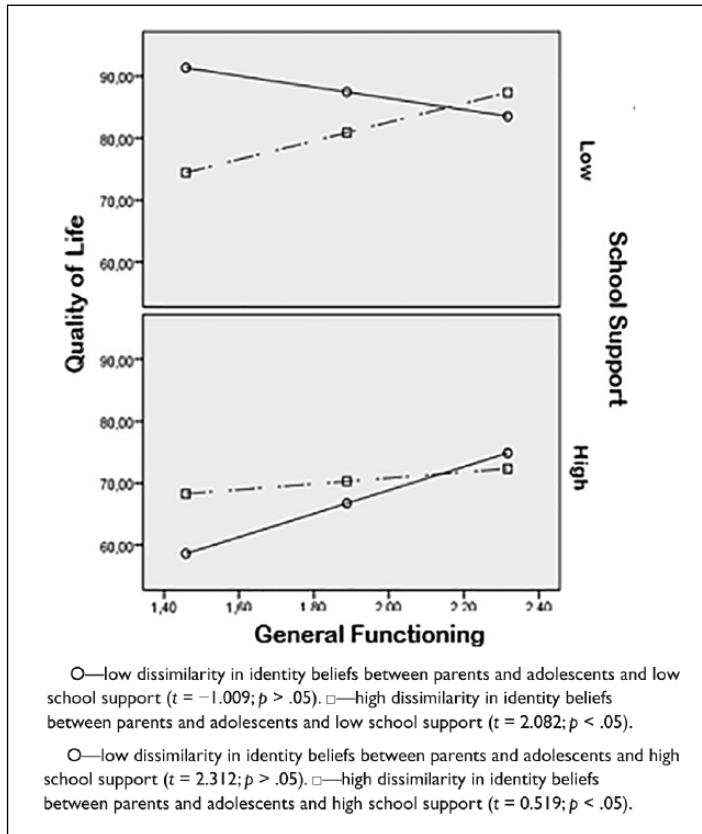


Figure 2. Moderating effect of school support and dissimilarity in identity perceptions between parents and adolescents on the relationship between general functioning and adolescents' QoL (three-way interaction with continuous moderators).

As the figure shows, the school support effect is separate for low and high dissimilarities in identity perceptions between parents and adolescents, regarding the negative relationship between family functioning (general functioning) and QoL. The interaction between dissimilarity in identity perceptions and general family functioning was only significant when school support was lower.

Hypothesis 1 assessed the association between study variables and QoL, and the results showed that higher school support and higher dissimilarities in illness representations between parents and adolescents were related with better QoL and worse family functioning was related with lower QoL. These results confirmed the hypothesis and are also consistent with the literature (Almeida et al., 2015; Heijmans et al., 1999; Law et al., 2002; Olsen et al., 2008; Skinner & Hampson, 2001). In fact, the normative developmental changes of adolescence with the consequent growing of autonomy and independence from parents may contribute to the association between higher dissimilarities in illness perceptions between parents and adolescents and better QoL (Miller & Drotar, 2003).

Only two moderated moderation were significant and confirmed hypotheses 2, that is, when school support was low and more dissimilarities in identity and concerns perceptions between parents and adolescents were both high, the relationship between family functioning and QoL was negative. Neither the study of Law (2002) nor the study of Olsen et al. (2008) found that

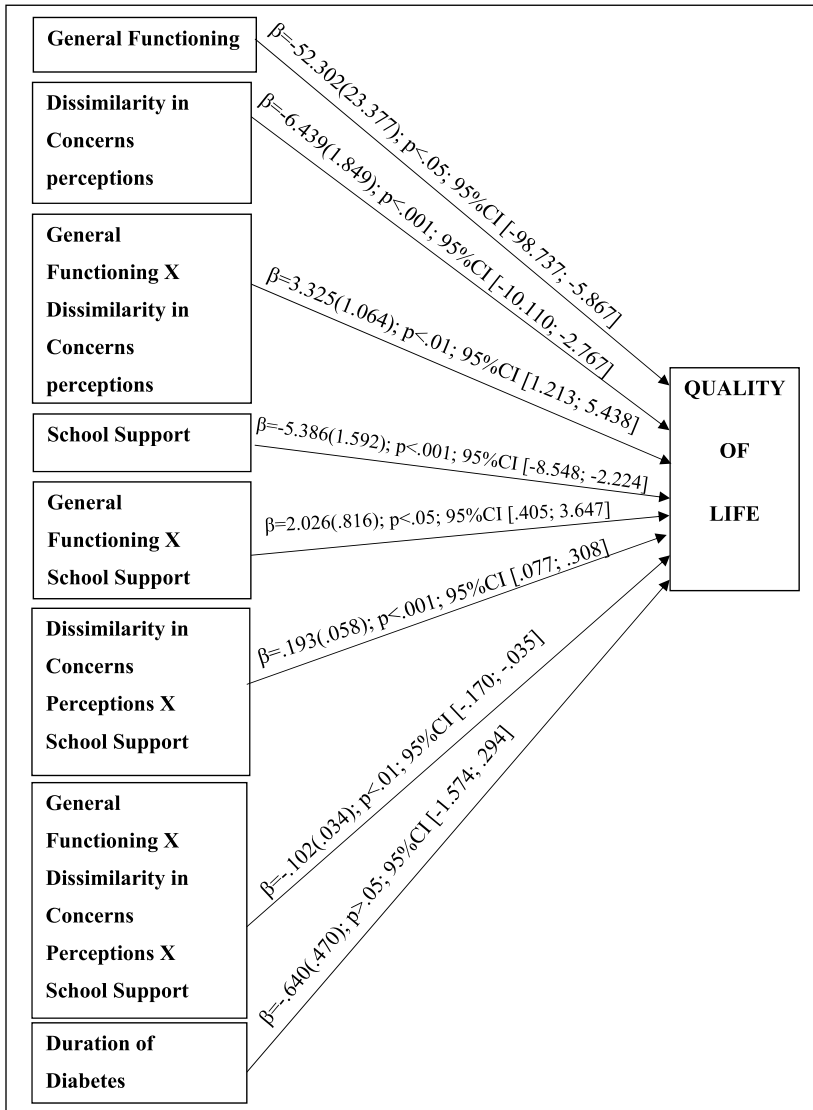


Figure 3. Dissimilarity in concerns perceptions, between parents and adolescents, and school support as moderators in the relationship between family functioning (general functioning) and QoL. β (standard error); 95% CI (lower limit of 95% confidence interval (LL 95% CI); upper limit of 95% confidence interval (UL 95% CI)).

dissimilarity in illness perceptions between parents and adolescents with T1D were associated with adolescents’ well-being. However, regarding the relationship of dissimilarity in illness perceptions between spouses and patient’s adaptation to Addison disease, Heijmans et al. (1999) study found that dissimilarity in perceptions of identity, timeline, and consequences were related to psychological adjustment. An overprotective behavior by spouses or attitudes that maximize the seriousness of the partner’s disease were negatively related to patients’ well-being (Heijmans et al., 1999).

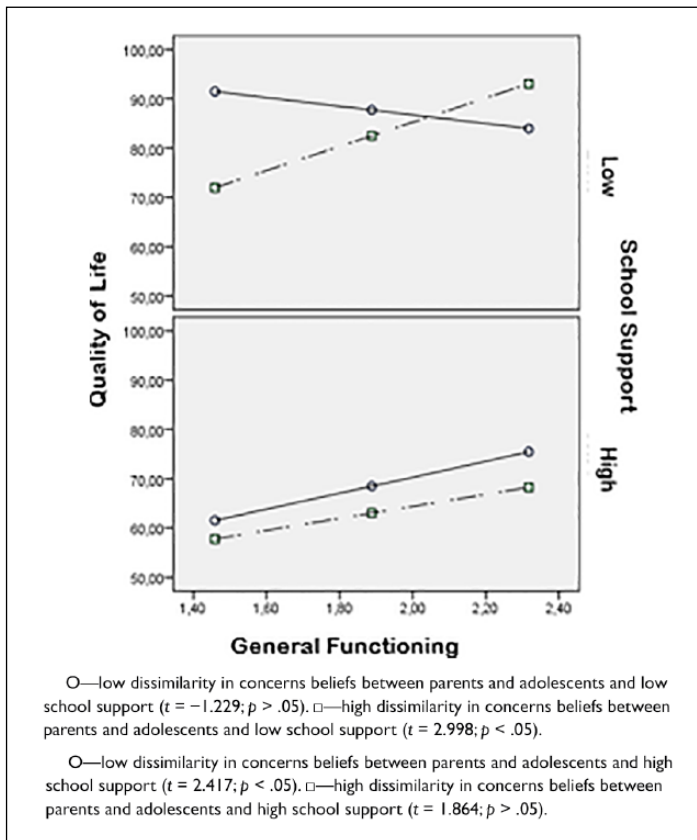


Figure 4. Moderating effect of school support and dissimilarity in concerns perceptions between parents and adolescents on the relationship between general functioning and adolescents' QoL (three-way interaction with continuous moderators).

As the figure show, the effect of school support is separate for low and high dissimilarities in concerns perceptions between parents and adolescents, regarding the negative relationship between family functioning (general functioning) and QoL. The interaction between dissimilarity in identity perceptions and general family functioning was only significant when school support was lower.

Although some studies only showed dissimilarities in some illness perceptions between parents and adolescents (Law, 2002; Law et al., 2002; Olsen et al., 2008), with parents perceiving more consequences and having more negative emotional perceptions than adolescents, and adolescents perceiving that their parents do not recognize their autonomy skills' in diabetes management (Butner et al., 2009). Maternal perceptions may condition who is responsible for diabetes management (Law et al., 2002). An excessive sense of diabetes' threatening representations, fear of future complications and a strong belief in diabetes treatment may delay the process of transferring diabetes management from parents to adolescents (Miller & Drotar, 2003), which may result in family conflicts (Butner et al., 2009). Sometimes adolescents do not act according to their own beliefs, but rather behave as instructed by their parents regarding diabetes management, particularly if they are young (Skinner & Hampson, 2001).

Despite the high number of hours per day that adolescents engage in school activities, both adolescents with T1D and their parents reported that teachers and school staff still showed

inadequate knowledge about diabetes and few had training with diabetes tasks (Lehmkuhl & Nabors, 2008) resulting in low school support that was related with low QoL (Mandali & Gordon, 2009; Wagner et al., 2006). Nevertheless, when peers, teachers, and school staff were provided with adequate training and schools with better facilities and flexibility to accommodate adolescents' diabetes tasks, school support increased, and adolescents' QoL improved (Butler & Lawlor, 2004; Nabors et al., 2005; Wagner et al., 2006). In the same study, school personnel that received training stated that afterwards, they were able to understand the psychosocial impact that adolescents with diabetes had to face in their daily routines.

The development of social skills during adolescence has been related with better QoL, improved ability to manage the stress associated with the acceptance of diabetes diagnosis and with the incorporation of self-care in adolescents' daily routines (Edgar & Skinner, 2003). However, the fear of non-acceptance by peers or of being treated differently because of a diagnosis of diabetes (Mandali & Gordon, 2009) leads adolescents sometimes to deliberately not share their diagnosis and consciously skipping blood glucose monitoring, insulin injections, ignoring also carbon hydrates' intake, and forgetting to adjust insulin doses in school activities (Davidson et al., 2004). Although the importance of emotional support from friends has been well described (Bearman & La Grecca, 2002), adolescents with T1D still face internal stress and apprehension about the reactions of friends to the management of diabetes tasks, during school activities with peers, which may explain why low school support predicted low QoL.

The negative relationship between family functioning and QoL when school support was lower, and dissimilarity in concerns and identity perceptions between parents and adolescents were higher, may be explained by the adolescents' need for autonomy that may conflict with family's supervision and be interpreted as intrusive and, therefore, perceived as negative (Butner et al., 2009; Miller & Drotar, 2003). This result would also explain why adolescents and parents differ regarding concerns toward diabetes, particularly when the adolescent also has low support from school in dealing with diabetes tasks (Mandali & Gordon, 2009; Nabors et al., 2005).

This study presents some limitations such as the cross-sectional design with a convenience sample, which precludes causality between variables and may not be representative of all adolescents with T1D. All psychosocial variables in this study were measured with self-report instruments that may reflect adolescents' social pressure to provide socially acceptable answers. Only the Brief-IPQ (Broadbent et al., 2006), which was answered by both adolescents and parents, allowed the comparison in illness perceptions and their influence on diabetes outcomes. Thus, future research should include prospective studies to better study how family and school staff influence QoL in adolescents, during the entire adolescent period, while the developmental changes are occurring that may influence adolescent's perceptions and diabetes performance. From a heuristic point of view, longitudinal studies would help in designing intervention programs to promote school and family support in order to improve diabetes outcomes and avoid later complications in adolescents with T1D (Jaser & Grey, 2010).

Practical implications

Based on the results, intervention programs that contribute to parental supervision and negotiation skills are important in defining the shared responsibility of diabetes tasks between parents and adolescents. Such skills may help to prepare the transferring of responsibility of diabetes care to adolescents, according to their developmental skills. Also, the development of positive and supportive family communication patterns and problem solving related to diabetes management may improve family support and cohesion, avoiding family conflicts.

The strategies to support adolescents with T1D must include parents, friends, teachers, and school staff, who should work together to contribute to adolescents' QoL. The specific diabetes training for school staff may improve their knowledge regarding the tasks needed to manage diabetes, which may contribute to increase flexibility regarding school activities and better nutritional options, that may result in school support regarding adolescents with T1D.

Conclusion

This study shows that school support and dissimilarities in illness perceptions between parents and adolescents interact in the relationship between family functioning and QoL in adolescents with T1D. Therefore, interventions should include family, peers, and teachers in the management of T1D in adolescents.


Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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