Chapter Number

Predictors of Adherence, Metabolic Control and Quality of Life in Adolescents with Type 1 Diabetes

M. Graça Pereira[1], A. Cristina Almeida[2],
Liliana Rocha[1] and Engrácia Leandro[2]
[1]University of Minho, School of Psychology
[2]University of Minho , Social Sciences Institute
Portugal

1. Introduction

Diabetes Mellitus Type I (DM1) is a diagnosed disease that appears before age 35 (Hanas, 2007) and is well known, in the pediatric population, as one of the most common diseases (Serafino, 1990). The diagnosis occurs mostly in childhood and adolescence, often between ages 5 and 11 (Eiser, 1990).

The definition of adolescence is a bit controversial but OMS (1965) establishes adolescence between 10 and 19 years old. The beginning of adolescence starts with the appearance of the first biological changes of puberty. According to Erikson's theory of psychosocial development (Erikson, 1968), the central task of adolescence is the development of autonomy, identity and self integration (Barros, 2003). In fact, identity formation, in adolescence, requires a reorganization of capacities, desires, needs and interests in the adolescent, as well as a quest for more independence towards parents. Nevertheless, the difficulties, even in the well succeeded resolution of the psychosocial tasks, may result in "identity confusion" (Erikson, 1968). In adolescents with diabetes, the disease can be an additional stressor functioning as another factor that requires acceptation and self integration. Diabetes exposes adolescents to potentially unpleasant experiences (having to explain others about the disease, medical exams, etc.) that can limit or prevent normal development and life experiences in adolescence (Close et al., 1986). On the other hand, physiological and hormonal changes that take place in adolescence may increase insulin resistance contributing to a weak control of diabetes (Duarte, 2002). In short, adolescence is a developmental phase, marked by changes and identity formation ,that requires a permanent and dynamic adaptation of the adolescent, ranging from feelings of acceptation to anger/anxiety and even depression (Leite, 2005) that can affect adherence to therapy and adaptation to illness. It is important to keep in mind that *being adolescent* is more important than *being diabetic* (Burroughs et al., 1997).

1.1 Adherence and metabolic control

Adherence to therapy in chronic disease is considered one of the main problems that may end in treatment failure (Leite, 2005). Kristeller and Rodin, in 1984, suggested that adherence

to treatment was built on three dimensions: 1) Adherence (compliance) that refers to the degree of acceptance of the individual towards prescriptions and medical recommendation; 2) Adherence towards keeping and following the treatment that was agreed in the previous phase, and 3) Adherence (maintenance) to diabetes' self care tasks that have been integrated in the person's life style. Throughout these phases, the diabetic acquires control and develops the autonomy necessary in the maintenance phase.

Any detour from the treatment plan is defined as non adherence to therapy (Bishop, 1994) and can range from missing appointments, forgetting to take insulin (or take more or less than the prescribed amount) to not following the nutritional or the exercise plan. In DM1, adherence is often assessed through hemoglobin levels (HbA1c), (Sperling, 1996). The relationship between therapy adherence and metabolic control is complex and probably bidirectional i.e. low adherence to therapy is often preceded by a weak metabolic control and vice versa (Kakleas et al., 2009). However, there is some controversial regarding this issue. For some, HbA1c is the most valid indicator of adherence to therapy (DCCT, 1994) for others, there isn't a direct relationship between HbA1c and adherence (Silva et al., 2002).

The weak adherence to self-care in diabetes seems to result from a multifactor combination (Fagulha et al., 2004). Warren and Hixenbaugh, in 1998, found demographic variables to weakly predict adherence to self care in diabetes. Some studies have revealed that adolescents typically are less adherent to therapy than children, regarding insulin administration, exercise, nutrition and self monitoring of glucose (Hirschberg, 2001). Each adolescent apprehends and creates meanings about diabetes and its treatment's demands and how (s)he deals with them, in the social context, influences adherence to diabetes (Barros, 2003). Moreover, puberty changes, psychological dilemmas characteristic of adolescence (La Greca, 1992) and cognitive development may also contribute to an increase in non-adherence. Also, immaturity of thought, in adolescence, based on invulnerability may be one of the main causes of low adherence to diabetes treatment (Santos, 2001; Elkind, 1984), in adolescence.

In children and adolescents with diabetes, adherence is higher after diabetes diagnosis and deteriorates over time (Jacobson et al., 1987). On the other hand, non-adherence happens in average 3,5 years after the diagnosis and around age 15 (Anderson & Laffel, 1997). Compared to younger children and adults, adolescents exhibit poorer self-care behavior (Anderson et al., 1990) and poorer metabolic control (Kovacs et al., 1989).ADA (American Diabetes Association, 2003) recommends, as a therapeutic goal, that HbA1c stays below 7%.

Diabetics between 11 and 18 years old show a weak metabolic control (Mortensen et al., 1998; Fagulha et al., 2004). In the first years of diagnosis, lack of knowledge about the disease can affect metabolic control in children and adolescents (Butler et al., 2008) and, after this first phase, adolescents' compliance with treatment depends on adherence to self care tasks and to the degree of parenting supervision regarding disease management (Anderson et al., 1997). According to the authors, in an early phase, parents show more involvement in tasks related to treatment, particularly insulin administration, that best predicts metabolic control. However, throughout adolescence, parental involvement diminishes resulting in a decrease of adherence to therapy and, therefore, in a weak metabolic control.

Differences in adherence and metabolic control, in DM1, by gender, have been reported in the literature (Mortensenn & Hougaard, 1997). Girls tend to present a weaker adherence and poor metabolic control compared to boys. Girls enter puberty earlier than boys and a poor metabolic control is associated to normal physiological changes, in adolescence, such as increased levels of hormones responsible for insulin resistance (Carroll & Shade, 2005). However, other behavioral and psychosocial factors also tend to contribute to non-adherence in diabetes such as feeling reluctant in doing self monitoring of blood glucose, having irregular meals and not complying with the correct insulin doses.

Some studies show a relationship between bad metabolic control and family dysfunction, namely conflict in the family and low family cohesion, although this relationship has not been found in other studies. In fact, higher levels of cohesion and family stability have been related to better boundary definition between family subsystems and, as a result, more incentive to autonomy, more effective family communication and better metabolic control in diabetic adolescents (Fisher et al., 1982). Also, poor social support was found to predict bad metabolic control and low adherence to self care in diabetic adolescents (Fukunishi et al., 1998). In order to overcome the difficulties, related to adherence and metabolic control, it's important to concentrate on the adolescents' social competencies, family support and friends' support (Pereira & Almeida, 2008). There are several factors, that go beyond adherence to self care in diabetes, that can influence metabolic control. Therefore, a lack of a relationship between adherence and metabolic control may be due to insufficient rigorous efforts in adherence 's evaluation (McNabb, 1997).

1.2 Family functioning

The presence of a chronic disease, in a family's member, is a stressor for the entire family limiting the family's ability to go on with usual tasks and psychosocial roles requiring, as a result, flexibility in the family's system (Northam et al., 1996). Family functioning and a supportive parental style have been associated to better adherence to treatment (Manne et al., 1993). Conflict and family dysfunction predicted low adherence to self care in diabetes (Miller-Johnson et al., 1994) while higher levels of social support, cohesion and organization were associated to better metabolic control and adherence. Adolescents with better metabolic control seem to have parents that encourage independence, express feelings openly and communicate directly. On the other hand, adolescents with poor metabolic control have parents that are more critical, suspicious or indifferent to treatment (Anderson et al., 1981). However, the relationship between family functioning (cohesion, good communication, no conflict) and metabolic control is controversial since some studies found this association (Wysocki, 1993; Seiffge-krenke, 1998; La Greca & Thompson, 1998) but others have failed (Kovacs et al., 1989; Wysocki et al., 2001).

1.3 Family social support

Low adherence in diabetes has been associated to low family support and less parental supervision (Beveridge et al., 2006). In an initial phase, after diagnosis,   adolescents receive more supervision from parents and adherence is stronger compared to late adolescence, when there is an increasing worry with body image, sexuality and independence from parental and authority figures (Jacbson et al., 1987). Relationships with others, at home or at school, play an important role in adolescence (Papalia et al., 2001). In an attempt to prove

they belong and are like their peers, adolescents may abandon the therapeutic regimen (Fagulha et al., 2004). In fact, diabetes treatment does not help adherence i.e. daily insulin administration and the fact that diabetes treatment only avoids negative repercussions in the long term without bringing positive consequences, creates difficulties regarding adherence (Hanson et al., 1989).

Research has shown a relationship among social support, adolescents/family's characteristics and metabolic control in DM1 (Hanson et al., 1989; Wysocki, 1993). A family that provides warmth, advice, and adequate problem solving's strategies promotes adherence (Ellerton et al., 1996). From a developmental perspective, during childhood, parents assume the responsibility for the treatment regimen, however, in adolescence, the responsibility tends to be transferred to the adolescent and often, one or more treatment's components may not be followed. Family support is considered more important for younger adolescents or for those with a shorter duration of the disease (Stern & Zevon, 1990). Parents are the bigger suppliers of social support (more than friends) in diabetes treatment (Hanson et al., 1989) and, as a result, adolescents with parents less involved or with parents that provide poor support show less adherence to therapy and show a lower metabolic control. Nevertheless, in some studies, parental support has been positivity associated to adolescent's adherence but not to metabolic control (Hanson et al., 1989). The authors defend the hypothesis that family support may have a direct effect on adherence given parent's supervision over treatment's tasks. Due to the need for autonomy and independence, parents' support to deal with diabetes' psychosocial tasks may not always be desirable and adolescents may prefer to solve their problems alone or with friends' help.

1.4 Parental coping

There are few studies regarding parents' coping strategies towards diabetes. Some studies reveal that parents cope well with their children' diabetes (Macrodimitris & Endler, 2001) but others have problems adapting to the disease (e.g. Kovacs & Feinberg, 1982). Adequate coping strategies to deal with diabetes include family involvement and/or sharing tasks, participation of adolescent and family in support groups, knowledge about the disease, use of assertive behaviors in social environment and reorganization of meals. Recently, a study revealed differences between fathers and mothers regarding the use of coping strategies (Correia, 2010). Mothers show greater responsibility, in the daily care tasks of the diabetic adolescent, being responsible for blood glucose records, meals plan and insulin administration (Zanetti & Mendes, 2001). In fact, mothers often seek information regarding the onset and course of diabetes (Nunes & Dupas, 2004).

The strategies used by caregivers may create potential difficulties and obstacles to adherence and metabolic control in diabetes. Sometimes, when confronted with chronic disease, parents' response to stressful situations may lead to a family rupture influencing, as a result, the adolescent and family's adaptation to illness (Trindade, 2000). Some parents, after the diagnosis, cease participating in social parties and forbid the adolescent to eat sweets, transforming social interactions that involve food, in uncomfortable situations for the adolescent, particularly when related to peers (Nunes & Dupas, 2004). This type of coping strategies exacerbate dependency in the adolescent with diabetes increasing parent's stress since they feel they need to protect and control the adolescent in

1   all situations and, as a result, family life needs to be organized and centered on the
2   illness (Brito & Sadala, 2009).

1.5 Illness representations
4   The self regulation behavior model (Leventhal et al., 1992) emphasizes the importance of
5   beliefs regarding adherence to treatment. In fact, illness representations play a role in
6   personal decisions towards adherence to treatment, in diabetes' self care (Gonder-Frederick
7   et al., 2002). In adults, recent research found that illness representations regarding diabetes
8   accounted for the diversity in disease-related functioning (Petrie et al., 1996). Illness
9   representations are concerned with those variables that patients themselves believe to be
10 central to their experience of illness and its management. Edgar and Skinner, in 2003,
11 described Leventhal's five dimensions of illness representations (Leventhal et al, 1980;
12 Leventhal et al., 1984): *identity,* the label and symptoms associated with the illness (e.g.,
13 thirst); *cause,* beliefs about the factors responsible for the onset of illness; *timeline,*
14 perceptions about the duration of illness; *consequences,* illness expected outcomes regarding
15 physical, psychological, social, and economic functioning on a daily basis and in the long
16 term; and *control/cure/treatment,* beliefs regarding the cure of the disease and patient's
17 control   over it. Later research, extended the original model adding more items by splitting
18 the control dimension into personal control and treatment control; including also a cyclical
19 timeline dimension; an overall comprehension of illness, and finally, an emotional
20 representation of the illness (Moss-Morris et al., 2002).
21 In adolescents with diabetes, illness representations have been associated to medical and
22 psychological outcomes. In particular, treatment effectiveness' beliefs have been associated
23 to self-care (Griva et al., 2000; Skinner & Hampson, 2001; Skinner et al., 2002) and perceived
24 consequences to lower levels of emotional well-being (Skinner et al., 2000; Skinner &
25 Hampson, 2001).   Illness representations, particularly consequences and emotional
26 representations have been found to predict quality of life (Paddison et al., 2008). The belief
27 that diabetes was a temporary disease, than a lifelong condition, and the perception that
28 diabetes had serious consequences predicted poor metabolic control. Also a perception of
29 control, over the course of illness, has been positively associated to quality of life (Paddison
30 et al., 2008).

1.6 School support
32 Most of the research on DM1 focused on family support and its implications on adherence,
33 as previously described and did not take in consideration school's support. However,
34 managing a chronic illness in adolescents, who are trying to become independent from their
35 families and integrate in their peer group, is not easy (Holmbeck et al., 2000). In fact, as the
36 adolescent grows, peer relationships become paramount and an important source of
37 emotional support (Wysocki & Greco, 2006). However, research on the implications of peers
38 support on adherence, metabolic control and quality of life is scarce. Peer conflict has been
39 associated to poor metabolic control in girls (Hegelson et al., 2009) and friend support has
40 been related to adherence to blood glucose testing (Bearman & La Greca, 2002). Regardless
41 of whether support from friends is associated to diabetes self-care and metabolic control,
42 support from friends may always help adolescents to better adjust psychologically to
43 diabetes (La Greca et al., 1995).

1   When faced with the choice of appropriate self-care behavior, older adolescents have better
2   problem solving skills but are more vulnerable to non-adherence in the face of peer pressure
3   (Thomas et al., 1997). Another study showed that adolescents, who perceive their friends
4   reacting negatively to their diabetes' self-care behavior, report more stress which, in turn, is
5   associated to poor metabolic control (Hains et al., 2007).
6   Research examining the positive and negative aspects of friends and peers, on diabetes
7   outcomes and psychological well-being, is not clear. There seems to be more evidence that
8   conflictual relationships are more harmful than supportive relations are beneficial, which is
9   consistent with the literature on healthy adults (Helgson, 2006). Besides peers' support,
10 teachers' support is also important. A study found that 9 % of parents had to change glucose
11 monitoring and 16% changed treatment administration because of lack of support from
12 teachers (Amillategui et al., 2007). In fact, teachers in general need to be knowledgeable of
13 hyperglycemia and hypoglycemia's episodes in order to assist the adolescent if needed.
14 Support from friends and peers are key factors that help the integration of the adolescent
15 teenager in the school setting, facilitating adaptation to diabetes.
16 Although diabetes does not cause pain on adolescents, impacts nonetheless, the adolescent
17 and family's daily living and, therefore, the quality of life of all involved (Hanas, 2007) at
18 physical, emotional, social and family 's levels (Pereira et al., 2008).

19 **1.7 Quality of Life (QOL)**
20 Girls perceived lower levels of QOL compared to boys. Worries about metabolic control
21 increase with age but, regardless of gender, as age increases QOL decreases (Hoey et al., 2001).
22 Adolescents who monitor their glucose levels, several times a day, reported better quality of
23 life (Novato, 2009). The monitoring of blood glucose levels allows the teenager to know the
24 variation of blood sugar, over time, perceiving what behaviors impact metabolic control,
25 resulting in better quality of life (Novato, 2009). Regarding the association between quality of
26 life and adherence to self-care in diabetes, literature is contradictory. Diabetes treatment has
27 adverse effects on quality of life (Watkins et al., 2000). In fact, adolescents with diabetes need
28 to follow a set of requirements that can negatively impact the perception of their quality of life
29 and interaction with others. However, other studies conclude that adherence to diabetes care is
30 not related to quality of life (e.g. Snoek, 2000). Diabetics with good metabolic control
31 (measured through glycated hemoglobin) show better quality of life (e.g Glasgow et al., 1997;
32 Silva, 2003) however, in some studies, this relationships has not been found and, in other
33 studies, this relationship is very weak or does not exist (e.g. Grey et al., 1998; Laffel et al., 2003).
34 Family also plays an important role in the perception of adolescents' QOL because QOL is
35 affected by how the family deals with the disease (Hanson, 2001). Family conflict predicts
36 lower QOL in adolescents (Dickenson et al., 2003). Family environment was shown to
37 influence QOL as well as adherence and metabolic control in adolescents with diabetes
38 (Pereira et al., 2008).
39 While there is a growing interest in psychological issues in diabetes, it is important to
40 identify which variables predict better outcomes. The present study aims to answer this
41 question namely understanding the relationship between psychological variables and
42 diabetes outcomes. The purpose is to find the best predictors of adherence, metabolic control
43 and quality of life in adolescents with type 1 diabetes taking in consideration adolescent
44 variables and family variables. Due to the fact that research on adolescents and chronic

illness have failed to incorporate gender (Miller & La Greca, 2005), the present study considers gender in the regression models.

2. Methods

2.1 Sample characteristics
A convenient sample of 170 subjects participated in the study: 85 adolescents and 85 family members that accompanied the teenager to their routine medical appointments, in a diabetes pediatric unit in two central Hospitals, and in a Diabetics Association. All teens received treatment in the hospital and therefore no differences were present between the sample from the Diabetics Association versus Hospitals.
All participants (teenagers and family members) were volunteers. Adolescents' criteria for inclusion were: age between 12 and 19 years, fulfilling ISPAD (1995) criteria for the diagnosis of type 1 diabetes, having a diagnosis longer than a year, being in ambulatory treatment, absence of another chronic and/or mental disease, not being pregnant and having normal cognitive development.

2.2 Procedure
Questionnaires were answered separately by adolescents and family members after they had been informed of the study's goals and filled the informed consent. The value of glycated hemoglobin (HbA1c) was determined by a nurse who collected a drop of blood from the adolescent before the medical appointment. Criteria of good metabolic control was based on ISPAD (2009) i.e. smaller than 7,5% is considered optimal, 7,5% - 9,0% suboptimal and higher than 9%, high risk.

2.3 Instruments
2.3.1 Adolescents and parent
Clinical, Socio-Demographic Questionnaire (Pereira et al., 2010) that reports gender and age in adolescents and their family members as well as metabolic control (glycated hemoglobin) and duration of disease, in the adolescent.
Brief Illness Perception Questionnaire – Brief-IPQ – Broadbent et al. (2006), (Portuguese version of Figueiras & Alves, 2007). The Brief-IPQ is a 9 items questionnaire, measuring cognitive and emotional representations of illness, that includes nine dimensions of illness perceptions: consequences, timeline, personal control, treatment control, identity, concern, coherence, emotional representation and causal representations. Both adolescents and parents answered the questionnaire. *Higher results indicate a more threatening perception of illness.* Due to the fact that each subscale includes only one item, it is not possible to calculate an alpha. As a result, like in the original version, pearson correlations between dimensions were calculated. In adolescents, significant correlations were present between consequences and emotional representation (r=.635), personal control and coherence (r=.511) and personal control and treatment control (r=.371). In the family sample, significant correlations were obtained between consequences and emotional representation (r=.558), personal control and coherence (r=.522) and between concern and coherence (r=.324).

2.3.2 Adolescents
Self Care Inventory – SCI - La Greca, A. (1992), (Portuguese version of Almeida & Pereira, 2010). It´s a 14 items questionnaire assessing adherence to diabetes treatment's

recommendations regarding self care that includes four subscales: blood glucose regulation, insulin and food regulation, exercise and emergency precautions. *Higher results indicate more adherence.* Only the full scale was considered in the present study. Internal consistency in the original version was .80 and in this sample was .73.

Diabetes Family Behaviour Scale – DFBS – McKelvey et al., (1993), (Portuguese version of Almeida & Pereira (in press). DFBS is a 47 items questionnaire that assesses family support given to the adolescent in diabetes self care. It is composed of two subscales: Guidance-Control *(*15 items) and Warmth-Caring (15 items). The remaining 17 items do not belong to any of the subscales. *High results indicate less social support.* Internal consistency, in the original version, was .86, .81 and .79 for the full scale, guidance-control and warmth-caring, respectively. The Portuguese version showed an alpha of .91 (total scale), .76 (guidance-control) and .81 (warmth-caring.). In this study only the full scale was considered (alpha of .75).

Diabetes Quality of Life – DQoL - Ingersoll & Marrero (1991), (Portuguese version of Almeida & Pereira (2008). DQol is a 52 items questionnaire that assesses quality of life in patients with diabetes that includes three subscales: impact of diabetes (23 items); worries towards diabetes (11 items) and satisfaction (towards treatment: 7 items; towards life in general: 10 items) and one item that assesses health and quality of life. Higher results indicate lower quality of life. In the original version, the alpha for the total subscale was .92, followed by .86 (satisfaction), .85 (impact of diabetes) and .82 (worries towards diabetes). In this sample alphas were .89 (total scale), .71 (impact on diabetes), .82 (worries towards diabetes) and .87 (satisfaction). All the subscales were considered in the hypothesis testing.

School Support (Pereira & Almeida, 2009). School Support is a 6 items questionnaire that measures school support (e.g. healthy snacks available in cafeteria) and peer support regarding daily diabetes' management (e.g. feeling supported by fiends regarding diabetes). *Higher results indicate more school support. T*he alpha in this sample was .81.

2.3.3 Parent

Family Assessment Device – FAD – Epstein et al., (1983), (Portuguese version provided by Ryan et al., 2005). It´s a 60 items questionnaire distributed by seven subscales: Problems Solving, Communication, Roles, Affective Responsiveness; Affective Involvement; Behavior control and General Functioning. *Higher results indicate low family functioning.* In the original version, Epstein, Baldwin and Bishop (1983) found the following results: Problem solving: .74; Communication: .75; Roles: .72; Affective responsiveness: .83; Affective involvement: .78; Behavior Control: .72 and General Functioning: .92. Only the full scale was used in the present study and the alpha, in the present sample, was .93.

Coping Health Inventory for Parents – CHIP – McCubbin et al., (1983), (Portuguese version of Pereira & Almeida, 2001). CHIP is a 45 items questionnaire that measures parents' response to management of family life when they have a child who is seriously and/or chronically ill. It includes three subscales: 1) Maintaining family integration, cooperation and an optimist definition of the situation; 2) Maintaining social support, self-esteem and psychological stability; and 3) Understanding the medical situation through communication with other parents and consultation with medical staff. *Higher results indicate better coping*. In the original version, the alpha for the first and second subscale was .79 and .71 for the third. In this sample, alphas were: .65 for the first subscale, .79 for the second and .71 for the last subscale.

3. Data analysis

First, descriptive statistics were performed to find the rate of adherence to self-care, metabolic control and quality of life. Hierarchical regression analyses were later performed to identify the best predictors of adherence to self-care, metabolic control and quality of life. Due to the size of the sample, regression analysis were first performed taking in consideration all variables ,except illness perceptions, and later including only them in the regression equation. The first regression was performed using the method *enter* since the selection of variables was based on previous research. The second regression, due to its exploratory nature, was performed using the stepwise method.

For both regressions, the variables considered in the first step were socio-demographic and clinical variables i.e. gender of the adolescent, duration of disease and values of glycated hemoglobin. In the first regression analysis, the second step included adolescents' psychosocial variables i.e. family support, quality of life, adherence and school support. The third step included family variables i.e. family functioning and coping. In the second regression analysis, the second step included adolescents' illness perceptions and the third step included family member's illness perceptions.

4. Results

4.1 Sample caracteristics

The sample consisted of 85 adolescents, 51% males and 49% females. Their age ranged from 12 to 19 with an average of 15.13 (SD=1.97), 15.12 for males (SD=2.00) and 15.14 for females (SD=1.96). Glycated hemoglobin in the sample was, in average, 9.06 (SD=1.58) specifically 9.00 (SD=1.72) for boys and 9.13 (SD=1.44) for girls. Therefore, girls had a poor metabolic control than boys but they were all at high risk. Average of duration of diabetes was 6.61 years (SD=3.68) with boys being diagnosed longer (M=7.05 years; SD=4.10) than girls (M=6.17 years; SD=3.19). In our sample, girls reported better adherence to self-care, less social support, higher school support and family social support when compared to boys but differences were non-significant. Girls showed less quality of life than boys and this difference was significant (t(83)=-2.004; p=.048) (table 1).

Variables	Duration of Diabetes		Adherence		Metabolic Control		Quality of Life		Family Support		School Support	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Male	7.05	4.10	4.00	0.59	9.00	1.72	75.91	16.96	106.63	13.15	27.93	6.34
Female	6.17	3.19	4.13	0.40	9.13	1.44	83.55	18.19	107.81	11.73	28.21	5.92

Statistics: M (mean), SD (standard deviation)

Table 1. Characteristics of the Adolescents' Sample by Clinical, Socio-demographic and Psychosocial variables

1   74% of adolescents lived with their nuclear families, 15% belonged to monoparental
2   families, 9.4% to stepfamilies and, only, 1.2% lived in an extended family. 20% of family
3   members, who participated in the study, were fathers and 80% mothers. Average age for
4   fathers was 46 years (SD=4.55) and for mothers was 44 years (SD=6.19).

5   **4.2 Predictors of adherence, metabolic control and quality of life in adolescents on**
6   **gender, duration of disease, glycated hemoglobin, family support, school support and**
7   **parental coping**
8   When all variables were included in the model, adherence was predicted by gender of
9   adolescent (p<.05), glycated hemoglobin (p<.05) and family support (p<.001), explaining
10 30% of the total variance. None of the family variables predicted adherence. Taking in
11 consideration what a high score means, in each instrument, results showed that low
12 perception of family support, gender (being male) and high glycated hemoglobin (bad
13 metabolic control) predicted lower adherence to diabetes self-care.
14 Metabolic Control was predicted by family support (total) (p<.05), adherence (total) (p<.05),
15 quality of life (total) (p<.05) and parental coping (understanding the medical situation)
16 (p<.05), explaining 15.9% of total variance. As a result, higher adherence of adolescent to
17 self-care and parental understanding of the medical situation predicted lower levels of
18 glycated hemoglobin (better metabolic control). On the other hand, low quality of life and
19 low perception of family support predicted high values of glycated hemoglobin (poor
20 metabolic control).
21 Quality of life was predicted by gender (p<.05), glycated hemoglobin (p<.05) and school
22 support (total) (p<.01) explaining 26.5% of the total variance. Higher values of glycated
23 hemoglobin (poor metabolic control) predicted lower quality of life. On the other hand,
24 higher adherence and a higher school support predicted better quality of life. Like in
25 adherence, none of the family variables predicted quality of life, in adolescents. Table 2
26 shows the results.

27 **4.3 Predictors of adherence, metabolic control and quality of life in adolescents on**
28 **glycated hemoglobin and illness representations**
29 Overall, adherence was predicted by personal control of adolescent's illness representations
30 (p<.001) and family's representation of timeline (p<.05) explaining 20.3% of the total
31 variance. Thus, lower adolescents' perception of personal control predicted lower adherence
32 to self care and higher family perception of diabetes duration (timeline) predicted higher
33 adherence to self care, in adolescents.
34 Metabolic control, in adolescents, was predicted by emotional representation of adolescents'
35 illness perceptions (p<.001) and by family's perceptions of illness coherence (p<.05),
36 explaining 16.6% of the total variance. Therefore, higher adolescents' perception of
37 emotional representation (diabetes seen as a threatening disease) predicted higher values of
38 glycated hemoglobin (poor metabolic control) and lower family's comprehension of diabetes
39 predicted higher values of glycated hemoglobin.
40 Quality of life was predicted by glycated hemoglobin (p<.05), adolescent's perception of
41 consequences (p<.05) and emotional representation (p<.05) explaining 31.6% of the total
42 variance. Higher perception of the consequences of diabetes by adolescents and higher
43 perception of emotional representation (diabetes seen as a threatening disease) predicted
44 lower quality of life. None of the family variables predicted adolescent's quality of life.
45 Table 3 shows the results.

Variables	Adherence				Hemoglobin (Metabolic Control)				Quality of Life			
	ΔR^2	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2	B	SE B	β
Step 1	.071				-.023				.129			
Gender		-.133	.108	-.131		-.088	.350	-.028		-6.03	3.55	-.175
Duration of disease		-.011	.015	-.081		-.009	.048	-.020		-.369	.487	-.078
Glycated Hemoglobin		-.092	.034	**-.286****		----	----	----		3.745	1.12	**.340*****
Step 2	.312				.132				.258			
Gender		-.207	.096	**-.204***		-.123	.342	-.039		-7.91	3.36	**-.229***
Duration of disease		.001	.013	.005		.014	.046	.033		-.295	.464	-.062
Glycated Hemoglobin		-.077	.032	**-.239***		----	----	----		2.35	1.128	**.214***
Family Support		-.019	.004	**-.466*****		-.029	.015	-.232		-.104	.159	-.075
School Support		-.003	.009	-.030		-.018	.030	-.070		-.937	.287	**-.325****
Adherence		----	---	----		-.932	.381	**-.301***		-7.89	3.92	**-.232***
Quality of Life		-.006	.003	**-.215***		.023	.011	**.250***		-	-	-
Step 3	.300				.159				.265			
Gender		-.214	.097	**-.211***		-.160	.338	-.051		-6.97	3.389	**-.202***
Duration of disease		.001	.013	.006		.018	.045	.042		-.211	.465	-.045
Glycated Hemoglobin		-.085	.033	**-.262***		----	----	----		2.34	1.16	**.213***
Family Support		-.019	.004	**-.459*****		-.032	.015	**-.251***		-.146	.161	-.105
School Support		-.000	.009	-.008		-.015	.030	-.058		-.958	.292	**-.332****
Adherence		----	---	----		-.976	.378	**-.315***		-6.865	3.976	-.202
Quality of Life		-.006	.003	-.192		.022	.011	**.244***		----	----	----
Family Functioning		-.099	.162	-.060		.146	.549	.029		9.008	5.554	.162
Coping –Medical Situation		-.019	.016	-.124		-.116	.052	**-.248***		.414	.547	.080
Coping - Social Support		.002	.007	.026		.018	.023	.086		-.274	.238	-.119

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

Table 2. Predictors of Adherence, Metabolic Control and Quality of Life in Adolescents on Gender, Duration of Disease, Glycated Hemoglobin, Family Support, School Support and Parental Coping (N=85 adolescents; N= 85 family members)

Variables	Adherence				Hemoglobin (Metabolic Control)				Quality of Life			
	ΔR^2	B	SE B	β	ΔR^2	B	SE B	β	ΔR^2	B	SE B	β
Step 1	.070				n.s.				.121			
Glycated Hemoglobin		-.092	.034	-.285**						4.117	1.160	.363***
Step 2	.169				.126				.288			
Glycated Hemoglobin												
Consequences - IPQ Adol.												
Personal Control - IPQ Adol.		-.081	.024	-.350***						2.820	1.083	.249*
Emotional Representation - IPQ Adol.						.180	.050	.369***		2.762	.612	.431***
Step 3	.203				.166.				.316			
Glycated Hemoglobin												
Consequences - IPQ Adol.												
Personal Control - IPQ Adol.		-.084	.024	-.364***						2.197	1.102	.194*
Emotional Representation - IPQ Adol.		.046	.022	.206*		.173	.049	.356***		1.822	.749	.284*
Timeline - IPQ Family										1.402	.670	.254*
Coherence - IPQ Family						.154	.069.	.224*				

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

Table 3. Predictors of Adherence, Metabolic Control and Quality of Life in Adolescents on Glycated Hemoglobin and Illness Representations (N=85 adolescents; N= 85 fam. members)

5. Discussion

In this study, adolescent's gender (i.e. being male) predicted lower adherence to diabetes self-care and higher quality of life. An association between gender and low adherence to diabetes, in adolescents girls, particularly regarding exercise, has been found in the literature (Patino et al., 2005). Girls with diabetes show lower quality of life than boys because they seemed to worry more regarding their illness (Grey et al., 1998; Rocha, 2010; Hoey et al., 2001). In fact, low quality of life, in girls, has been associated to more difficulties and worries regarding diabetes and less satisfaction with metabolic control. Girls enter puberty earlier than boys and a weak metabolic control may be associated to physiological changes, normal to adolescence, such as increased levels of hormones responsible for insulin resistance (Carroll & Shade, 2005).

In terms of predictors of **a**dherence, taking in consideration the final model, higher values of glycated hemoglobin (poor metabolic control) predicted lower adherence to diabetes self-care and lower quality of life. These results are in accordance with the literature. Adolescents have more difficulties with metabolic control suggesting that hormonal changes, associated with puberty and the decline on adherence to self-care, were responsible for these results (Helgeson et al., 2009). In another study, glycated hemoglobin explained a small variance of quality of life in adolescents with diabetes suggesting that higher levels of glycated hemoglobin (poor metabolic control) had negative effects on the adolescent's perception of quality of life (Malik & Koot, 2009). In a study that addressed metabolic control and quality of life, good metabolic control (measured by glycated hemoglobin) was a predictor of better quality of life (Hoey et al.,2005).

Higher family support predicted higher adherence and better metabolic control (lower levels of glycated hemoglobin). These results are in accordance with the literature. Family support has been found to be a predictor of good metabolic control (Lewin et al., 2006). In fact, low family support was associated to low adherence to diabetes self-care and, indirectly, to a poor metabolic control. La Greca and Bearman, in 2002, suggested that family support predicts adolescents' adherence to diabetes self-care because family support is an important factor on the daily management of diabetes' self-care tasks in adolescents. Higher family support was found to be a predictor of higher adherence to self-care and good metabolic control suggesting the direct impact of parental support on diabetes' management tasks   influencing , as a result, adherence and metabolic control, in the adolescent (Duke et al., 2008; Ellis et al., 2007). In a Portuguese sample of adolescents, family support was found to predict adherence in adolescents with type 1 diabetes (Pereira et al., 2008).

In the present study, a lower perception of personal control predicted lower adherence to diabetes self-care in adolescents. Beliefs in the effectiveness of treatment (control over the illness) were found to predict adherence to dietary self-care (Delamater, 2009). When the benefits, compared to costs of following the diabetes regimen were considered lower, diabetes was perceived as a less threatening disease and adherence to self care in diabetes , as a result, was poor (Patino et al., 2005).

Higher family perception of diabetes' duration, as an illness, predicted higher adherence of adolescents to diabetes self-care. In an attempt to understand if there were differences between illness representations in adults with type 2 diabetes and their partners, a relationship was found between partner's perceptions of the duration of diabetes (timeline) and treatment suggesting that partners' perceptions could influence positively patients' adherence to diabetes self-care (Searle et al., 2007). Based on these result, the same may be true for the dyads parent-adolescent. In fact, parent's perception as a long last condition in

adolescent's life may be associated to more parental support regarding diabetes' management tasks in order to decrease future complications in the adolescent.

In terms of predictors of metabolic control, higher adherence to diabetes self-care predicted better metabolic control (lower levels of glycated hemoglobin). In fact, higher adherence to diabetes self-care has been found to predict good metabolic control in adolescents with type 1 diabetes, and lower quality of life, on the other hand, to predict poor metabolic control (Lewin et al., 2009). Higher levels of glycated hemoglobin have been associated to more worries regarding diabetes having, therefore, a negative impact on quality of life (Guttmann-Bauman et al., 1998).

Parents' understanding of the medical situation (coping with diabetes) predicted lower levels of glycated hemoglobin (better metabolic control) in the adolescent. This is a very interesting result. Family environment is important in the complex mechanism of adaptation to diabetes self-care having also an impact on metabolic control (Grey & Berry, 2004). In a study about behavioral therapy with families of adolescents with diabetes, when the relationship between parents and adolescents with diabetes improved, parents´ coping with their adolescents' diabetes got better producing also better outcomes, such as good metabolic control in the adolescent (Wysocki et al., 2000).

Adolescent's emotional representation of diabetes (as a threatening disease) predicted higher levels of glycated haemoglobin (poor metabolic control). In a study about health beliefs in adolescents with type 1 diabetes, negative illness perception, like illness severity and susceptibility were predictors of poor metabolic control. On the other hand, lower family's comprehension (illness coherence) of diabetes predicted bad metabolic control in the adolescent. This result emphasizes the importance of parents' understanding of the impact of diabetes on their child suggesting that those parents who understand less the disease may exercise less parental supervision and provide less family support regarding diabetes's management and, as a consequence, metabolic control decreases.

In terms of quality of life, higher school support predicted higher quality of life. This result is in accordance with the literature. Peers relationships are paramount on the psychological well-being of adolescents with diabetes (Helgeson et al., 2009). In fact, relationships with peers can positively or negatively (e.g. conflict experiences) influence quality of life of adolescents with type 1 diabetes. Adolescents who have more positive attitudes with their school experience tended to experience lower problems and worries with diabetes's management (Lehmkuhl & Nabors, 2007).

Lower quality of life was predicted by higher perceptions of diabetes consequences and higher perceptions of emotional representation (more threatening). This result is in accordance with the literature. In fact, using the same illness perceptions questionnaire, with adults with type 2 diabetes, lower quality of life was found to be related to stronger beliefs of diabetes consequences and negative emotional representations (Edgar et al., 2003). Also, in another study, illness beliefs predicted quality of life i.e. consequences and emotional representations of diabetes were found to predict low quality of life in adolescents (Paddison et al., 2008).

6. Conclusion

In this study, the importance of family factors (family support and parental coping) become evident on diabetes outcomes. As a result, it is important to include parents on intervention programs regarding diabetes in adolescence, School support is also an important factor and

future studies should address how peers, teachers and school environment may help or hinder adherence, metabolic control and quality of life. According to results, psychological interventions should be included in the treatment protocol of adolescents receiving medical treatment.

Adolescents and parents' illness representations were predictors of adherence, metabolic control and quality of life, showing the importance of these constructs on diabetes outcomes and should, therefore, be included in intervention programs. Future studies should address how contradictory illness representations between parents and adolescents impact diabetes outcomes particularly if the adolescent perceives parents as intrusive trying to force their diabetes' representations on them.

It would be also interesting to assess family functioning from the adolescent point of view, besides parents' perspective (the only one addressed in the present study) and find out whether parents and adolescents' different perspectives, regarding family functioning, may impact diabetes outcomes.

7. References

Almeida, J. & Pereira, M. G. (no prelo). *Escala Comportamental de Suporte Social Familiar para Adolescentes com Diabetes* (DFBS).

Almeida, J. & Pereira, M.G. (2008). Questionário de Avaliação da Qualidade de Vida para Adolescentes com Diabetes: Estudo de validação do DQOL. *Análise Psicológica*, 2 (26), 295-307.

American Diabetes Association (2003). Test of Glycemia in Diabetes. Clinical Pratice Recommendations. *Diabetes Care*, 26 (1), 106-108.

Amillategui, B. , Calle, J. R. , Alvarez, M. A. Cardiel, M. A., & Barrio, R. (2007). Identifying the special needs of children with Type 1 diabetes in the school setting. An overview of parents' perceptions. *Diabetic Medicine,* 24(10), 1073-1079.

Amoros, M., Sanchez, J., & Carrillo, F. (2003). Adherencia al tratamiento. In Quiles, Sebastian & Carrillo (Eds.), *Manual de Psicología de la Salud con Niños, Adolescentes y Familia*, (pp. 73-94). Ediciones Pirâmide: Madrid.

Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, J. P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology*, 15, 477-492.

Anderson, B., Brackett, J, Finkelstein, D., & Laffel, L. (1997). Parental Involvement in Diabetes Management Tasks: Relations to Blood Glucose Monitoring and Metabolic Control in Adolescents with Insulin-Dependent Diabetes-Mellitus. *The Journal of Pediatrics*, 130 (2), 257-265.

Anderson, B.J., & Laffel, L.M.B. (1997). Behavioral and psychology research with school aged children with type 1 diabetes. *Diabetes Spectrum,* 10 (4), 277-284.

Anderson, B.J., Miller, P., Auslander, W.F., & Santiago, J.V. (1981). Family Characteristics of Diabetic Adolescents: Relationship to Metabolic Control. *Diabetes Care*, 4, 586-594.

Barros, L. (2003). *Psicologia Pediátrica: perspectiva desenvolvimentista*. 2ªEdição. Climepsi Editores: Lisboa.

Bearman, K. J., & La Greca, A. M. (2002). Assessing friend support of adolescents' diabetes care: the diabetes social support questionnaire-friends version. *Journal of Pediatric Psychology*, 27(5), 417-428.

Beveridge, R.M., Berg, C.A., Wiebe, D.J., & Palmer, D.L. (2006). Mother and Adolescent representations of illness ownership and stressful events surrounding diabetes. *Journal of Pediatrics Psychology*, 31, 818-827.

Bishop, G. (1994). Interacting with the health care system. In Bishop (Ed.), *Health Psychology: Integrating mind and body* (pp. 220-227). Needham-Heights: Allyn and Bacon.

Brito, T.B., & Sadala, M.L.A. (2009). Diabetes mellitus juvenil: a experiência de familiares de adolescentes e pré-adolescentes. *Ciência & Saúde Coletiva,* 14 (3), 947-960.

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60 631- 637.

Burroughs, T.E., Harris, M.A., Pontious, S.L., & Santiago, J.V. (1997). Research on social support in adolescents with IDDM: A critical review. *Diabetes Educator*, 23, 438-448.

Butler, D.A., Zuehlke, J.B., Tovar, A., Volkening, L.K., Anderson, B.J., & Laffel, L.M.B. (2008). The impact of modifiable family factors on glycemic control among youth with type 1 diabetes. *Pediatric Diabetes*, 9 (Part II), 373-381.

Cameron, F. J., Skinner, T. C., De Heaufort, C. E., Hoey, H., Swift, P. G. F., Aanstoot, H. et al., (2008). Are family factors universally related to metabolic outcomes in adolescents with type 1 Diabetes? *Diabetes Medicine,* 25 (4), 463-468.

Carroll M.F & Shade D.S. (2001). Ten pivotal questions about diabetic ketoacidosis. *Postgraduate Medicine*, 110, 89 –95.

Close H, Davies AG, Price DA, Goodyer IM. (1986). Emotional difficulties in diabetes mellitus. *Archives of Diseases Childhood.* 61(4), 337–340 .

Correia, A.C.R. (2010). *Coping e Auto-Eficácia em Pais de Crianças e Adolescentes com Diabetes tipo 1.* Tese de Mestrado em Psicologia Clínica e da Saúde não publicada. Faculdade de Ciências Humanas e Sociais. Porto. Portugal.

Delamater, A. M. (2009). Psychological care of children and adolescents with diabetes. *Pediatric Diabetes*, 10 (Suppl. 12), 175-184.

Diabetes Control and Complications Trial Research Group (DCCT) (1994). Effect of intensive diabetes treatment on the development and progression of long term complications in adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics*, 12, 177-188.

Dickenson, L.M., Ye, X., Sack, J., & Hueston, W.(2003). General quality of life in youth with diabetes: Relationship to patient management and Diabetes – Specific Family and Conflict. *Diabetes Care*, 26, 3067-3073.

Duarte, R. (2002). *Epidemiologia da Diabetes.* In R. Duarte, J. Caldeira, J. Parreira, L. Sagreira, A. Odette & P. Lisboa (Eds). *Diabetologia Clínica*, Lidel - Edições Técnicas Lda. Lisboa.

Duke, D. C., Geffken, G. R., Lewin, A. B., Williams, L. B., Storch, E. A., & Silverstein, J. H. (2008). Glycemic Control in Youth with Type 1 Diabetes: Family Predictors and Mediators. *Journal of Pediatric Psychology*, 33 (7), 719-727.

Edgar, R. A. & Skinner, T. C. (2003). Illness Representation and Coping as Predictors of Emotional Well-being in Adolescents with Type 1 Diabetes. *Journal of Pediatric Psychology*, 28 (7), 485-493.

Eiser, C. 1990). *Chronic Childhood Disease*. New York: Cambridge University Press.

Elkind, D. (1984). *All grown up and no place to go: Teenagers in crisis*. Reading, MA: Add is on-Wesley.

Ellerton, M. L.; Stewart, M. J., Ritchie, J. A., & Hirth, A. M. (1996). Social support in children with a chronic condition. *Canadian Journal of Nursing Research*, 28 (4), 15-36.

Ellis, D. A., Podolski, C. L., Frey, M., Naar-King, S., Wang, B., & Moltz, K. (2007). The Role of Parental Monitoring in Adolescent Health Outcomes: Impact on Regimen Adherence in Youth with Type 1 Diabetes. *Journal of Pediatric Psychology*, 32(8), 907-917.

Epstein, N., Baldwin, L. & Bishop, D. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*, 9, 171-180.

Erikson, E. H. (1968) .*Identity, Youth and Crisis*. New York: Norton

Fagulha, A., Santos, I., & Grupo de Estudo da Diabetes (2004). Controlo glicémico e tratamento da Diabetes tipo 1 da Criança e Adolescente em Portugal. *Acta Médica Portuguesa*, 17, 173-179.

Figueiras, M.J. & Alves, N. C.(2007). Lay perceptions of serious illnesses: An adapted version of the Revised Illness Perception Questionnaire (IPQ-R) for healthy people. *Psychology and Health*, 22 (2), 143-158.

Fisher, E.B., Delamater, A.M., Bertelson, A.D., & Kirkley, B.G. (1982). Psychological factors in diabetes and its treatment. *Journal of Consulting and Clinical Psychology*, *50*(6), 993-1003.

Fukunishi, I., Akimoto, M., Horikawa, N., Shirasaka, K., & Yamazaki, T. (1998). Stress and Social Support in glucose tolerance abnormality. *Journal of Psychosomatic Research,* 45 (4), 362-269.

Glasgow, R. E., Ruggiero, L., Eakin, E. G., Dryfoos, J., & Chobanian, L. (1997). Quality of life and associated characteristics in a large national sample of adults with diabetes. *Diabetes Care, 20* (4), 562-567.

Gonder-Frederick, L., Cox, D. J., & Ritterband, L. M. (2002). Diabetes and behavioral medicine: The second decade. *Journal of Consulting and Clinical Psychology*, 70(3), 611-625

Grey, M. & Berry, D. (2004). Coping Skills Training and Problem Solving in Diabetes. *Current Diabetes Reports*, 4, 126-131.

Grey, M., Boland, E., Yu, C., Sullivan-Bollyai, A., & Tamborlane, W.V. (1998). Personal and Family Factors Associated with Quality of Life in Adolescents with Diabetes. *Diabetes Care*, 212 (6), 909-914.

Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self-efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology and Health, 15*, 733–750.

Guttmann-Bauman, I., Flaherty, B. P., Strugger, M. & McEvoy, R. C. (1998). Metabolic Control and Quality-of-Life Self-Assessment in Adolescents With IDDM. *Diabetes Care*, 21 (6), 915-918.

Hanas, R. (2007). *Diabetes Tipo 1 em Crianças, Adolescentes e Jovens Adultos*. Abbott Diabetes Care. Lidel - Edições técnicas Lda: Lisboa.

Hanson, C. L., Cigrang, J. A., Harris, M. A., Carle, D. L., Relyea, G., & Burghen, G. A. (1989). Coping styles in youths with insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology, 57*, 644–651.

Hanson, C.L. (2001). Quality of life in families of youths with chronic conditions. In H.M. Koot & J.L. Wallander (Eds.), *Quality of life in child and adolescent illness: Concepts, methods and findings* (pp. 182-209). New York: Brunner-Routledge.

Haynes, A., Bower, C., Bulsara, M. K., Finn, J., Jones, T. W. and Davis, E. A. (2007), Perinatal risk factors for childhood Type 1 diabetes in Western Australia—a population-based study (1980–2002). *Diabetic Medicine*, 24, 564–570.

Helgeson, V. S., Lopez, L. C., & Kamarck, T. (2009). Peer Relationships and Diabetes: Retrospective and Ecological Momentary Assessment Approaches. *Health Psychology*. 28(3), 273-282.

Helgeson, V. S., Siminerio, L., Escobar, O. & Becker, D. (2009). Predictors of Metabolic Control among Adolescents with Diabetes: A 4-Year Longitudinal Study. *Journal of Pediatric Psychology*, 34(3), 254–270.

Hirschberg, S.L. (2001). *The Self-regulation of health behaviour in children with insulin dependent diabetes mellitus.* Dissertation presented to the Faculty of Pacific Graduate School of Psychology. Palo Alto, California.

Hoey, H., Aanstoot, H. J., Chiarelli, F., Daneman, D., Danne, T., Dorchy, H. et al., (2001). Good Metabolic Control is Associated with Better Quality of Life in 2101 Adolescents with Type 1 Diabetes. *Diabetes Care*, 24 (11), 1923-1928.

Holmbeck, G. N., Colder, C., Shapera, W., Westhoven, V., Kenealy, L., & Updegrove, A. (2000). Working with adolescents: Guides from developmental psychology. In P. C. Kendall (Ed.), *Child and adolescent therapy: Cognitive behavioral procedures* (2nd ed.; pp. 334–385). New York: Guilford Press.

Ingersoll, G. & Marrero, D. (1991). A modified Quality of Life Measure for Youths: Psycometrics Properties. *The Diabetes Educator*, 17 (2), 114-118.

Jacobson A. M., Hauser, S. T., Wolfsdorf, J. I., Houlihan, J., Milley, J. E. & Watt, E. (1987). Psychological Predictors of Compliance in Children with Recent Onset of Diabetes Mellitus. *Journal of Pediatrics*, 805-811.

Kakleas, K., Kandyla, B., Karayianni, C., & Karavanaki, K. (2009). Psychosocial problems in adolescents with Type 1 diabetes mellitus. *Diabetes & Metabolism*. University of Athens.

Kovacs, M., & Feinberg, T. (1982). Coping with juvenile onset diabetes mellitus. In A. Baum & J. Singer (Eds), *Handbook of Psychology and Health*, 2,165-212. Erlbaum: Hillsdale, NJ.

Kovacs, M., Kass, R. E., Schnell, T. M., Goldston, D., & Marsh, J. (1989). Family functioning and metabolic control of school-aged children with IDDM. Diabetes Care, 12, 409-414.

Kristeller, J. l., & Rodin, J. (1984). A Three-stage model of treatment continuity: compliance, adherence and maintenance. In A. Baum, S. Taylor & J. Singer (Eds.), *Handbook of Psychology and Health.* (Vol. IV, pp. 85-112). New Jersey: Lawrence Erlbaum Associates.

La Greca, A. M. (1992). *Brief Manual for the Self Care Inventory*. University of Miami.USA.

La Greca, A. M. (1992). Peer Influences in Pediatric Chronic Illness: An Update. *Journal of Pediatric Psychology*; 17 (6), 775-784.

La Greca, A. M., & Bearman, K. J. (2002). The Diabetes Social Support Questionnaire-Family Version: Evaluating Adolescents' Diabetes-Specific Support From Family Members. *Journal of Pediatric Psycholog*, 27 (8), 665-676.

La Greca, A. M., & Thompson, K.M (1998). Family and friend Support for Adolescents with Diabetes. *Análise Psicológica*, 1 (XVI), 101-113.

La Greca, A. M., Auslander, W. F., Greco, P., Spetter, D., Fisher, E. B., Jr., & Santiago, J. V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology, 20,* 449–476.

Laffel, L., Connell, A., Vangsness, L., Goebel-Fabri, A., Mansfield, A., & Anderson, B. (2003). General Quality of life in Youth with type 1 Diabetes. Relationship to patient management and diabetes-specific family conflit. *Diabetes Care*, 26, (11), 3067- 3073.

Lehmkuhl, H., & Nabors, L. (2007). Children with Diabetes: Satisfaction with School Support, Illness Perceptions and HbA1C Levels. *Journal of Developmental and Physical Disabilities*, 20, 101-114.

Leite (2005). Programa de promoção da adesão terapêutica em crianças diabéticas. In M. Guerra & L. Lima, (Eds.), *Intervenção Psicológica em Grupos em Contextos de Saúde*. Climepsi Editores: Lisboa.

Leventhal, H., Diefenbach, M.A., & Leventhal, E. A. (1992). Illness Cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, 16, 143-163.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense representation of illness danger. In S. Rachman (Ed.), *Contributions to Medical Psychology* (Vol. 2, pp. 7–30). New York: Pergamon Press.

Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representation and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of Psychology and Health* (pp. 219 –252). Hillsdale, NJ: Lawrence Erlbaum Associates.

Lewin, A. B., Heidgerken, A. D., Geffken, G. R., Williams, L. B., Storch, E. A., Gelfand, K. M. & al., (2006). The Relation Between Family Factors and Metabolic Control: The Role of Diabetes Adherence. *Journal of Pediatric Psychology*, 31 (2), 174-183.

Lewin, A. B., La Greca, A. M., Geffken, G. R., Williams, L. B., Duke, D. C., Storch, E. A. & et al., (2009). Validity and Reliability of an Adolescent and Parent Rating Scale of Type 1 Diabetes Adherence Behaviors: The Self-Care Inventory (SCI). *Journal of Pediatric Psychology*, 34(9), 999-1007.

Macrodimitris S.D., & Endler N.S. (2001). Coping, control, and adjustment in Type 2 diabetes. Health Psychology, 20(3), 208-16.

Malik, J. A., & Koot, H. M. (2009). Explaining the Adjustment of Adolescents With Type 1 Diabetes. Role of diabetes-specific and psychosocial factors. *Diabetes Care*, 32, 774-779.

Manne, S.L., Jacobson, P.B.,Gorfinkle,K., Gerstein, F., & Redd, W.H. (1993).Treatment adherence diffilculties among children with cancer: the role of parenting style. *Journal of Pediatric Psychology,* 18 (1), 47-62.

McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, A.E., Wilson, L. R., & Warwick, W. (1983). CHIP – Coping Health Inventory for Parents: An Assessment of Parental Coping Patterns in the Care of the Chronically Ill Child. *Journal of Marriage and Family*, 359-370.

McKelvey, J., Waller, D. A., North, A. J., Marks, J. F., Schreiner, B., Travis, L. B., & Murphy, J.N. Reliability and Validity of the Diabetes Family Behavior Scale (DFBS). *The Diabetes Educator*, 19, 125-132.

McNabb, W. L. (1997). Adherence in diabetes: can we define it an can we measure it? *Diabetes Care*, 20 (2), 215-218.

Miller, K. B., & La Greca, A. M. (2005). Adjustment to chronic illness in girls. In D. J. Bell, S. L. Foster, & E. J. Mash (Eds.), *Handbook of behavioral and emotional problems in girls* (pp. 489–522). New York: Kluwer Academic/Plenum Press Publishers.

Miller-Johnson, Emery, R, Marvin, R., Clarke, W., Loevinger, R., & Martin, M. (1994). Parent-Child Relationships And The Management Of Insulin-Dependent Diabetes Mellitus. *Journal of Consulting and Clinical Psychology*, 62 (3), 603-610.

Mortensen, H., Hougaard, P., & Hvidore Study Group (1997). Comparison of metabolic control in a cross-sectional study of 2873 children and adolescentts with IDDM from 18 countries. *Diabetes Care,* 20, 714-720.

Mortensen, H.B., Robertson, K.J., Aanstoot, H.J. Danne, T., Holl, R.H., Hougaard, P., et al., (1998). Insulin management and metabolic control of Type 1 diabetes mellitus in childhood and adolescence in 18 countries. Diabetic Medicine, 15, 752–759,

Moss-Morris, R., Weinman J., Petrie, K.J. Horn, R., Cameron, L. & Buick, D. (2002). The Revised Illness Perception Questionnaire (IPQ-R). Psychology and Health ,17 (1), 1-16.

Northam, E, Anderson, P, Adler, R., & Warne, M. (1996). Psychosocial and Family Functioning In Children with Insulin-Dependent Diabetes at Diagnosis and One Year Later. *Journal of Pediatric Psychology, 21*, 699-717.

Novato, T.S. (2009). *Factores preditivos de Qualidade de Vida Relacionada à Saúde em Adolescentes com Diabetes Mellitus tipo 1.* Tese não publicada de Pós-Graduação em Enfermagem na Saúde do Adulto. Brasil.

Nunes, M.D.R. & Dupas, G. (2004). Entregando-se à vivência da doença do filho: a experiência da mãe da criança/adolescente diabético. *Texto e Contexto de Enfermagem*, 13 (1), 83-91.

Olsen, B., Berg, C. A. and Wiebe, D. J. (2005). Dissimilarity in mother and adolescent illness representations of type 1 diabetes and negative emotional adjustment. *Psychology and Health*, 23 (1), 113-129.

Organización Mundial de la Salud (1965).Problemas de salud de la adolescência. Série de Informes técnicos, Geneva: OMS, 308,29p.

Paddison, C.A.M., Alpass, F.M., & Stephens, C.V. (2008). Psychological variables account for variation in metabolic control and quality of life among people with type 2 diabetes in New Zealand. *International Journal of Behavioural Medicine* 15: 180–186, 2008.

Papalia, D., Olds, S., & Feldman, R. (2001). *O Mundo da criança*. McGraw-Hill: Lisboa.

Patino, A. M., Sanchez, J., Eidson, M., & Delamater, A. M. (2005). Health Beliefs and Regimen Adherence in Minority Adolescents with Type 1 Diabetes. *Journal of Pediatric Psychology*, 30 (6), 503-512.

Pereira, M. G., & Almeida, J. P. (2001). CHIP – *Coping Health Inventory for Parents: An Assessment of Parental Coping Patterns in the Care of the Chronically Ill Child*. Research Version of University of Minho.Braga.Portugal.

Pereira, M.G., Berg-Cross, L., Almeida, P., & Machado, C. J. (2008). Impact of Family Environment and Support and Adherence, Metabolic Control, and Quality Life in Adolescents with Diabetes. *International Journal of Behavioral Medicine,* 15, 187-193.

Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: Longitudinal study. *British Medical Journal, 312,* 1191–1194..

Ray, C., Epstein N., Keitner, G., Miller, I., & Bishop, D. (2005). Evaluation and Treating Families: The McMaster Approach. *Routledge Taylor & Francis Group*. New York.

Rocha. L. (2010). *Variáveis familiares, adesão, controlo metabólico e qualidade de vida na diabetes tipo 1:* Um estudo com adolescentes e familiares Unpublished dissertation. University of Minho. Braga. Portugal.

Santos, R. J. (2001). *Adolescentes com Diabetes Mellitus Tipo 1: Seu cotidiano e enfrentamento da doença*. Dissertação apresentada ao Programa de Pós-Graduação em Psicologia da Universidade Federal do Espírito Santo. Brasil.

Sarafino, E. P. (1990). *Health psychology: Biopsychosocial Interactions*. New York: John Wiley & Sons.

Searle, A., Norman, P., Thompson, R., & Vedhara, R. (2007). Illness representations among patients with type 2 diabetes and their partners: Relationships with self-management behaviours. *Journal of Psychosomatic Research*, 63, 175-184.

Seiffe-Krenke, I.(1998). Psychological Adjustment of Adolescents with Diabetes: Functional or Dysfunctional for Metabolic Control? *Journal of Pediatric Psychology*, 23 (5), 313-322.

Silva, I. (2003). *Qualidade de vida e variáveis psicológicas associadas a sequelas de diabetes e sua evolução ao longo do tempo.* Tese de Doutoramento não publicada, Faculdade de Psicologia e de Ciências da Educação, Universidade do Porto.Portugal.

Silva, I., Pais Ribeiro, J., Cardoso, H., & Ramos, H. (2002). Questionário de Auto-cuidados na Diabetes – contributo para a criação de um instrumento de avaliação da adesão ao tratamento. *Psiquiatria Clínica*, 23 (3), 227-237.

Skinner T. C., Hampson S. E., & Fife-Schaw, C. (2002). Personality, personal model beliefs, and self-care in adolescents and young adults with Type 1 diabetes. *Health Psychology, 21,* 61–70.

Skinner, T. C., & Hampson, S. E. (2001). Personal models of diabetes in relation to self-care, well-being, and glycemic control: A prospective study in adolescence. *Diabetes Care, 24,* 828–833.

Skinner, T. C., John, M., & Hampson, S. E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: A longitudinal study of adolescents with diabetes. *Journal of Pediatric Psychology, 25*(4), 257–267.

Snoek F.J., Pouwer F., Welch G.W., & Polonsky WH.(2000). Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. *Diabetes Care*, 23(9), 1305-9.

Sperling, A. M. (1996). Diabetes Mellitus. In W. Nelson, R. Behrman, & A.Arvin (Ed.). *Nelson Textbook of Pediatrics,* 15ª Edição, WB Sanders & Company: Philadelphia.

Stern, M. & Zevon, M.A (1990). Stress, Coping and Family Environment: the Adolescent's Response to Naturally Occurring Stressors. *Journal of Adolescent Research*, 5, 290-305.

Thomas, A. M., Peterson, L., & Goldstein, D. (1997). Problem solving and diabetes regimen adherence by children and adolescents with IDDM in social pressure situations: A reflection of normal development. *Journal of Pediatric Psychology, 22,* 541–561.

Trindade, I. (2000). Abordagem Psicológica do doente crónico em centros de saúde. In I.Trindade, & J. Teixeira (Eds), Psicologia nos cuidados de saúde primários (pp. 47-53). Climepsi Editores: Lisboa.

Warren, L. & Hixenbaugh, P. (1998). Adherence and Diabetes. In L.B. Myers, & K. Midence (Eds), *Adherence to treatment in medical conditions* (pp.423-453). Harwood Academic Publishers: Netherlands

Watkins K.W., Klem L, Connell C.M., Hickey, T., Fitzgerald. J.T., Ingersoll-Dayton B. (2000) Effect of adults self-regulation of diabetes on quality of life. *Diabetes Care* 2000; 23, 1511–1515.

Wysocki et al. (2000). Randomized, Controlled Trial of Behavior Therapy for Families of Adolescents with Insulin-Dependent Diabetes Mellitus. Journal of Pediatric Psychology, 25 (1), 23-33.

Wysocki, T (1993). Associations Among Teen-Parent Relationships, Metabolic Control, and Adjustment to Diabetes in Adolescents. *Journal of Pediatric Psychology*, 18 (4), 441-452.

Wysocki, T., & Greco, P. (2006). Social support and diabetes management in childhood and adolescence: Influence of parents and friends. *Current Diabetes Reports, 6,* 117–122.

Wysocki*, T., Greco, P., Harris, M. A., Bubb, J., & White, N. H. (2001). Behavior therapy for families of adolescents with IDDM: Maintenance of treatment effects. Diabetes Care, 24, 441–446.*

Zanetti, M.L. & Mendes, I.A.C. (2001). Análise das actividades relacionadas às actividades diárias de crianças e adolescentes com diabetes mellitus tipo1: depoimento de mães. *Revista Latino-Americana de Enfermagem*, 9 (6), 25-30.