

Adherence to treatment and health perceptions among youth with diabetes mellitus in Portugal

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Abstract

Few studies concerning the relationship of diabetes treatment with health perceptions among youth diagnosed with diabetes mellitus in Portugal have been conducted. Therefore, the aims of this research are to evaluate the levels of treatment adherence in a sample of diabetic youth, in order to measure the relationship between the perception of health status and treatment adherence levels. Furthermore, the study also intends to identify differences according to age, gender, parental support, the support of friends, and medical support. 68 youth participated in this study (45.6% male, 54.4% female). The mean age of the participants was 18.74 years (SD=4.18) and 95.6% were diagnosed with type-1 diabetes. The study used a socio-demographic questionnaire, the 36 Item Short-Form Health Survey, in addition to the Summary of Diabetes Self-care Activities Measures (SDSCA) as measurement instruments. Regarding the adherence to behavioral prescriptions, results showed a high level of compliance with the recommended instructions among all participants. Significant differences for several dimensions of adherence were found when comparing groups defined by gender, age, family support, friends support, and medical support. Correlational analyses show that the perception of general health is related to the levels of adherence to diabetes therapy. The implications of these results are discussed.

Introduction

Diabetes Mellitus (DM) is one of the leading chronic diseases of children and adolescents. It affects 1.82 out of every 1,000 young people in the United States [1] and 0.16% of the Portuguese population aged from 0 to 19 years of age [2]. Although the majority of youth with diabetes have type-1 diabetes, type-2 diabetes has also been reported. Individuals with DM are typically placed on a strict and complex maintenance regimen that involves regular administration of insulin through injections, attention to diet and exercise, and monitoring glucose levels, while making the appropriate treatment adjustments. Although self-care is often challenging for all age groups, a significant number of children and adolescents fail to adhere to physician directives and do not receive adequate self-care [3,4].

The goal of treatment is to maintain optimal glycemic control so that hypo and hyperglycemic episodes are avoided. Excessively low or high levels of blood glucose are contraindicated because they can substantially increase the risk of serious medical complications, including retinopathy, nephropathy, neuropathy, heart disease, limited joint mobility, and even a shortened life span [5]. The number and complexity of the different tasks involved in managing DM can be overwhelming, even for the most competent patient. This is especially apparent for adolescents, who are concurrently coping with various developmental tasks ranging from dramatic physical changes to increasing peer pressure [6]. Concerns about adolescents being especially vulnerable to poor adherence have been largely generated by empirical research, which reveals that children with diabetes tend to show a precipitous decline in glycemic control as they enter adolescence. Several variables have been linked to poor adherence, such as a lack of parental involvement, a lack of peer support, external locus of control, a lack of self-efficacy, and negative health beliefs [7,8].

Some studies explored dietary adherence, namely eating behaviors, consuming sufficient macronutrients, and following

dietary recommendations. Rates of adherence to recommended eating behaviors ranged from 21% to 95% [9]. Other studies explored the importance of intrapersonal variables, such as conscientiousness, neuroticism personality domains, and one or more self-reported adherence behaviors [10]. Quantitative research into barriers to treatment adherence has identified a range of factors including: costs and access to treatments, the complexity and demands of the treatment regimen, and a lack of social support and depression [11]. Research into promoting treatment adherence has found that the most effective interventions are complex and include combinations of more convenient care, information, reminders, specific behavioral change techniques [12,13], and the involvement of patients in the decision-making process [14].

Regarding the quality of life among youth with DM, most studies emphasize the importance of family factors (family support and parental coping), adolescents and parents' illness representations [15], the impact of treatment, and depression or difficulty managing the disease [16] as mediators of quality of life. However, other studies demonstrate that age, gender, a high BMI, poor metabolic control, and the intensity of treatment did not influence the quality of life of children with diabetes [17].

Few existing studies explore the relationship between the perception of health status and adherence to diabetes treatment among young people. Thus, we sought to examine whether better health perceptions

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lead to increased or decreased levels of adherence to treatment in this population. The following specific objectives were outlined: to evaluate the levels of adherence to treatment in diabetic young people; to evaluate the relationship between the perception of health status and the levels of adherence to treatment; and to identify differences according to age, gender, parental support, friends support, and medical support.

Materials and methods

Participants

A convenience sample of Portuguese youth with diabetes between 11 and 30 years old was selected to participate in a cross-sectional study. The study involved 68 youth, of whom 31 were male (45.6%) and 37 were female (54.4%). The mean age of the sample was 18.74 years (SD= 4.18). In order to better describe the participants and enhance the analysis of the results, the sample was divided into two groups. The first group consisted of subjects between 11 and 18 years old (adolescents), while the second group was composed of subjects ranging from 19 to 28 years old (young adults). All participants attend school or university, and the majority (60.3%) stated that they did not practice any type of extracurricular activity.

Regarding the type of diabetes, the vast majority of participants (95.6%) suffer from type-1 diabetes. The average age of diagnosis was 13.24 years (SD=5.11). Data on the age when participants began treatment was similar to the age of diagnosis, with participants beginning treatment at 13.21 years of age (SD=5.14) on average. Regarding the treatment of diabetes, it was found that 95.6% of all participants use insulin to treat diabetes, 2.9% use pills, and 1.5% use only dietary recommendations.

In regard to the difficulties experienced with treatment, we found that 58.8% of youth claim to have difficulty following the recommended dietary prescriptions for diabetes. Only 25% say that they have difficulties with physical exercise, and the majority of the study participants (77.9%) claim that they experience some difficulties with their treatment.

Instruments

The socio-demographic questionnaire aimed to collect essential information for the study, such as age, sex, educational level, socioeconomic status, and the practice of extracurricular activities. This questionnaire also included questions concerning the type of diabetes, the age of diagnosis, the type of treatment, the age of participants when starting diabetes treatment, any specific difficulties with treatment, and the support received from significant others.

36 Item Short-Form Health Survey

The 36-Item Short Form Health Survey (SF-36) is a tool used to facilitate administration and understanding, and allows for the generic evaluation of quality of life [18]. It is an instrument consisting of 36 items grouped into eight dimensions: functional capacity (limitations in usual activities due to health issues), physical aspects (limitations in physical activities due to health problems), pain (physical pain), general health (perception that the subject has of his/her health in general), vitality (energy and fatigue), social aspects (limitations in usual activities due to physical or emotional problems), emotional aspects (limitations in usual activities due to emotional problems), and mental health (psychological distress and well-being). The final score of the dimensions is obtained from the sum of the corresponding items and is transformed into a percentage, where 0% corresponds to worse general health status and 100% to better health status.

Summary of diabetes self-care activities measures (SDSCA)

The SDSCA was built with the purpose of evaluating the adherence to self-care activities in diabetic patients [19] and is the most widely used instrument in research on this topic [20]. In total, the scale consists of 19 items, and is parameterized utilizing the number of days per week, where participants indicate the weekly frequency of various activities. Thus, the score ranges from 0 to 7 for each item, taking into account the indicated weekly frequency. The items are grouped into six dimensions, namely: diet, exercise, foot care, glycemic control, drug treatment, and smoking. A Portuguese version of the SDSCA was used in this study (Cronbach's $\alpha=0.81$) [21].

Procedures

Before collecting the data, the instruments were subjected to a pre-test with 10 subjects (5 female and 5 male) in order to check for possible flaws, ambiguities, or incorrect questions. Parallel to this process, initial contact was made with a General Hospital from the National Portuguese Health Service and the Association of Young Diabetics of Portugal, in order to get permission from these institutions to collect data. The questionnaires were made available in print, and all ethical guidelines were met, namely informed consent and confidentiality. The questionnaires collected in the selected Hospital and in the Association were delivered together with the informed consent form and the completed questionnaires were returned via the use of a sealed envelope. 75 questionnaires were collected, but 7 were eliminated due to incorrect completion.

Results

Regarding the adherence to behavioral prescriptions, the results showed that compliance with the recommended instructions was as follows: 75% (51) say that they follow a restricted diet for diabetes, 41.2% (28) report physical activity, and 54.4% (37) take care of their feet. Regarding adherence to glycemic control, it was found that most respondents 80.9% (55) show high levels of adherence to this practice. As for smoking, results indicate that only 12 participants (17.6%) smoke. Finally, concerning the adherence to medication (insulin), virtually the entire sample (95.6%) demonstrates good adherence to this aspect of diabetes treatment.

In order to compare differences in the adherence to treatment and behavioral practices between age groups (younger and older youth), the non-parametric Mann-Whitney U test was used. No statistically significant differences were found for the five dimensions of adherence, except for smoking. Younger participants were found to smoke less, thus revealing higher levels of adherence when compared with older participants ($U=469$, $W=1030$; $p=0.04$) (Table 1).

Table 2 shows the results for the correlation analysis between health perception levels and adherence. Thus, in regard to diet, significant and positive results were obtained concerning functional ability ($r=0.24$; $p<0.05$), general health ($r=0.49$, $p<0.001$), vitality ($r=0.47$; $p<0.001$), social aspects ($r=0.03$; $p<0.05$), emotional aspects ($r=0.25$; $p<0.05$), and mental health ($r=0.34$; $p<0.001$). Therefore, it can be assumed that as we increase the levels of functional capacity, general health, vitality, social and emotional aspects, and mental health, this will result in increased adherence to the dietary recommendations for diabetes patients,

As for exercise, significant results were obtained in relation to functional ability ($r=0.25$; $p<0.05$) and vitality ($r=0.34$; $p<0.001$). Thus, the frequency of exercise increases with increased functional capacity and vitality.

Table 1. Adherence results grouped by age, gender, parental support, friends support, and medical support.

		Diet	U; p	Physical activity	U; p	Glycemic control	U; p	Foot care	U; p	Smoking	U; p	Insulin administration	U; p
Age	Younger	35.23	552;0.68	32.16	495;0.24	34.20	567; 0.85	33.49	542; 0.61	37.59	469; 0.04*	36.00	525; 0.05*
	Older	33.73		36.98		34.82		35.58		31.23		32.91	
Gender	Male	33.13	531; 0.49	34.76	565; 0.90	33.32	537;0.51	37.94	467; 0.13	32.82	521; 0.33	36.00	527;0.11
	Female	35.65		34.28		35.49		31.62		35.91		33.24	
Parental Support	Yes	34.77	169; 0.62	34.76	170;0.68	34.42	181; 0.87	34.65	177; 0.82	35.56	120; 0.03*	34.35	177;0.58
	No	31.67		31.83		35.33		33.00		23.50		36.00	
Friends support	Yes	36.39	508;0.27	40.33	366;0.00*	34.39	572; 0.94	37.72	460; 0.10	38.61	428; 0.01*	35.06	
	No	32.38		27.94		34.63		30.88		29.88		33.88	556; 0.50
Medical support	Yes	31.90	338;0.02*	33.68	427;0.52	33.37	410; 0.27	34.73	454; 0.86	34.26	453; 0.80	33.92	437; 0.27
	No	41.21		36.61		37.42		33.89		35.13		36.00	

* $p \leq 0.05$ ** $p \leq 0.001$

Table 2. Results for the correlational analysis between health perception and adherence.

	Diet	Physical activity	Glycemic control	Foot care	Smoking	Insulin administration
Functional capacity	0.24*	0.25*	-0.07	-0.07	-0.07	0.15
Body pain	0.10	-0.01	0.02	0.16	-0.01	0.09
General health	0.49**	0.23	0.27*	0.40**	-0.00	0.14
Vitality	0.47**	0.34**	-0.07	0.35**	0.06	0.17
Social functioning	0.33**	0.18	0.16	0.26*	-0.04	0.10
Physical performance	0.18	0.02	-0.08	0.12	-0.14	-0.11
Emotional performance	0.25*	0.21	0.11	0.23	0.06	0.01

* $p \leq 0.05$ ** $p \leq 0.001$

Considering glycemic control, it can be observed that the only significant obtained value concerns the general state of health ($r=0.27$; $p < 0.05$), which means that adherence to glycemic control increases when participants' general health status increases.

Regarding foot care, positive and significant values were obtained for the general state of health ($r=0.40$; $p < 0.001$), vitality ($r=0.35$; $p < 0.001$), and social aspects ($r=0.26$; $p < 0.001$). Thus, it can be observed that adherence to the recommended foot care for diabetic patient's increases in conjunction with a greater perception of general health, a greater sense of vitality, and greater social performance. No significant values were obtained for smoking and insulin administration.

Discussion

A review of the literature reveals that there is a poor adherence to therapy among diabetic patients [22]. In this sense, several studies have shown that during adolescence levels of treatment adherence are lower and metabolic control is also worse [23,24]. However, in this study, young people in the sample presented high levels of adherence to diabetes therapy in all of the parameters examined. Thus, while childhood and adolescence are developmental phases marked by the development of different cognitive and social skills that may affect behavior, in relation to compliance with diabetes treatment and metabolic control, in the end these developmental changes may not be that influential [25].

Concerning the relationship between adherence levels and gender differences, some studies show differences in the adherence to diabetes treatment between men and women [26-28]. Yet, in this sample the differences were not statistically significant, which may suggest that gender has no influence on the adherence to the treatment of diabetes. However, female participants presented higher levels of adherence, and it was also found that the females smoked less than males, contributing to their improved treatment adherence. On the other

hand, males recorded higher levels of physical activity, foot care, and drug treatment. These results are concordant with some studies that found higher adherence to drug therapy among males when compared to females [29-31].

In regards to family support, the results indicate statistically significant differences only between the perception of parental support and smoking. For the remaining dimensions of adherence, the results did not show any statistically significant differences. This is possibly due to the heterogeneity of the groups where there is a discrepancy in the percentage distribution and where only six participants' report not receiving support from their parents. Nevertheless, it was found that young people that perceive to have support from their parents have higher levels of adherence to diet, physical exercise, better foot care, and smoke less than those who do not have such support. However, young people who do not feel supported by their parents show higher levels of adherence to glycemic control and insulin administration (drug treatment), when compared with young people who report receiving support from their parents. The latter results may suggest that the perceived support may be negative, inflicting pressure, stress, and anxiety, since positive support is associated with improved metabolic control [32,33]. These results may also suggest that young people who do not feel supported by their parents may demonstrate greater autonomy and responsibility concerning their treatment [34,35].

Concerning adherence levels to diet, exercise, and foot care, the results indicate that young people who perceive themselves to have support from their parents, present more of these behaviors and smoke less, which is consistent with other studies [36]. In this sense, family support appears to play a key role in issues pertaining to the adherence and management of therapeutic regimens for diabetes, by collaborating in carrying out some self-care activities such as monitoring blood glucose, foot care, and medication administration. Social support,

in particular family support, can be a valuable emotional coping strategy that plays a fundamental role in adherence to therapy and disease control.

Analyzing the relationship between the perception of support from friends and adherence levels, results only show statistically significant differences regarding exercise and smoking habits. A possible explanation for these results is related to the fact that most physical activities involve more than one person, and likely involve one's friends. Thus, it can be assumed that belonging to a friend group that encourages youth to engage in physical activity can be a decisive influence on the adherence to exercise recommendations. Although there are not significant differences for other dimensions, results indicate that young people who feel supported by their friends also have higher levels of adherence to a recommended diet for diabetes, improved foot care, and better adherence to drug treatment (insulin), when compared to those who do not perceive such support. This emphasizes the importance of one's peer group in adapting to diabetes treatment adherence and clinical development [37].

Regarding the relationship between the perception of medical support and adherence, results only show statistically significant differences concerning diet. Although among all other dimensions of adherence no statistically significant differences were found, we observe that young people who do not perceive to benefit from medical support have higher levels of adherence to physical activity, glycemic control, drug treatment (insulin administration), and smoke less when compared with those who feel like they receive support from their doctor. These results indicate that medical support does not seem to play a role in adherence to therapy. This can be explained by the fact that the support given by doctor tends to be a negative form of support, with a greater focus on pressure and criticism, rather than praise and the encouragement of positive behaviors.

The importance of studying how young diabetics evaluate their state of health and their treatment adherence is of the foremost importance because it has many implications for all those involved in the process of dealing with the disease. Correlational analysis demonstrates that there is a relationship between the perception that young people have about their health status and their adherence to the treatment of diabetes in its different dimensions. For instance, results indicate that following a recommended diet for diabetes increases levels of functional capacity, general health, social and emotional vitality, and mental health. This was also the case for young people who have a better perception about their general health, who feel more energetic, and who have higher levels of well-being. Therefore, it can be assumed that young people who perceive themselves as having fewer limitations in daily activities due to a health condition, or as a result of physical and/or emotional problems, show higher levels of adherence to the recommended diet for diabetes.

With regard to the levels of adherence to physical exercise recommendations, we observe that young people who perceive themselves to have fewer limitations in daily physical activities due to health problems, and who feel more energetic tend to have higher levels of adherence to the recommended exercise for the treatment of diabetes.

Adherence to glycemic control seems to be influenced by the general state of one's health, and the results indicate that a better perception of one's overall health leads to higher levels of adherence to glycemic control. Thus, it appears that young people who have a better

perception about their general health tend to have better adherence to the recommended glycemic control for diabetes.

Regarding foot care, the results indicate that a higher perception of general health, vitality, and social performance are correlated with better foot care. Thus, young people who perceive themselves as enjoying good general health, who have a greater sense of vitality, and who consider themselves to have fewer limitations in usual activities due to physical or emotional problems, tend to have improved foot care.

However, the results concerning the dimensions of adherence to drug treatment and smoking habits indicate that the levels of adherence to these dimensions do not seem to be influenced by any dimension regarding the perception of general health.

Finally, we conclude that the perception that young people have about their general health is related to the levels of adherence to diabetes therapy. Thus, young people who perceive themselves as having fewer limitations, both in daily physical activities due to health problems or due to physical and/or emotional problems, have a better perception of their general health. In addition, greater feelings of well-being and vitality seem to lead to higher levels of adherence to the recommended prescriptions for diabetic care, namely diet, physical activity, glycemic control, and foot care.

Not many studies about diabetes in adolescents or young adults exist in Portugal, and the scarcity of studies on the perception of health status and its relation to adherence to treatment and recommendations warrants further research. Despite the fact that this is a relatively small sample, which compromises the generalization of results, this study is an important contribution on which future research can be based.

Implications for clinical practice

The long-term medical, educational, psycho-emotional, and social effects that occur from daily diabetes management among diabetic youths should be taken into consideration when offering primary care. Prior research has focused on the physiological and not the psychological implications of intensive diabetic treatment programs for adolescents. A better understanding of the challenges faced by adolescents with diabetes will provide a clearer direction to focus future efforts of multidisciplinary, multisystem teamwork by medical professionals.

An important implication of this study is that it demonstrates how the style and quality of medical care can better influence adherence to treatment and behavioral recommendations, given that clinical research populations of children and youth with diabetes often lack the understanding of relational factors. In addition, given recent advances in diabetes treatment (e.g., pump therapy), it will be important for future research to examine diabetes care and adherence in relation to specific forms of treatment. Finally, this research suggests that parents and children's agreement to adhere to care regimens varies with the quality of parental support. This information has implications for clinicians when identifying which whether information provided by parents, children, or both should be involved in the assessment of diabetes adherence.

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