Active participation and perceived barriers among adolescents with diabetes mellitus
Chapter 6

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Abstract

The aim of this study was to assess among adolescents with diabetes mellitus (DM) the associations of perceived parental and personal worries with DM-related limitations in social relationships, exercising, leisure-time activities and activities at school. The sample consisted of 68 Slovak adolescents (aged 11 to 16 years, 48.5% boys) with DM type 1 who regularly attended diabetic outpatient settings. We collected data on adolescent-reported parental and own worries using the Diabetes Quality of Life for Youth questionnaire. Logistic regression models adjusted for gender were used. Adolescents who reported more parental worries also reported more DM-related limitations in social relationships (odds ratio (OR)/95% confidence interval (CI): 1.03/1.00-1.07), leisure-time activities (OR/CI: 1.03/1.00-1.06) and activities at school (OR/CI: 1.04/1.00-1.07). On the other hand, their personal worries were associated only with limitations in social relationships (OR/CI: 1.04/1.00-1.08) and in exercising (OR/CI: 1.06/1.02-1.09).

Conclusions: Parental as well personal worries seem to be important factors associated with perceived limitations of adolescents with DM in their participation in life.

Key words: active participation, perceived barriers, adolescence, diabetes mellitus
Introduction
Diabetes mellitus type 1 (DM-1) is one of the most common chronic diseases in adolescents, and the incidence is increasing in many countries worldwide, particularly in children under the age of 15 years (IDF, 2015). The management of DM-1 affects every aspect of an adolescent’s physical and emotional growth and development. It requires significant lifestyle changes, which put a substantial burden on adolescents and their families (Clarke, 2011). As a result of these changes and various complications, the diagnosis of DM-1 is a stress factor not only for the adolescents themselves, but also for their parents.

Participation describes the extent to which a child is socially engaged in child-relevant life situations, such as social relationships, home life and education or organized leisure-time activities in school (King et al., 2007), and this is at stake in DM in particular. Adolescents with a chronic condition are more likely than their peers to miss school due to their condition or treatment, which may affect their school attendance (Michaud et al., 2007). Moreover, because of various limitations related to their treatment and changes of lifestyle or just because they use medicines, adolescents with a chronic condition may feel different from their peers. This may lead to exclusion from their peer group and social isolation (Suris et al., 2004). At the same time, experience of high levels of family stress or conflicts over management is associated with poorer adherence to treatment (Michaud et al., 2007). In addition, Leclair et al. (2013) suggest that children with DM-1 are less engaged in physical activities and do not meet the recommendations of the World Health Organization of accumulation at least 60 minutes of moderate-to-vigorous physical activity per day (2010). However, participation of these children is affected not only by their health condition but also by personal factors and is also connected with perceived internal or external barriers to participation (Shields et al., 2012).

Therefore, the aim of the study is to explore the association of perceived personal and parental barriers with DM-related limitations in particular to participation in social relationships, exercising, activities at school and leisure-time activities.

Methods
Sample and procedure
The study was conducted in 2014 and 2016 in two outpatient clinics in Bratislava and Kosice, the two biggest cities in Slovakia, serving patients in the surrounding regions. Respondents who were visiting these clinics and met the inclusion criteria (age from 11 to 15 years, diagnosis of DM-1 lasting at least one year) (N=68) were asked to fill in the questionnaire by a trained diabetic nurse in an out-patient setting. Parents were informed about the study via the diabetes nurses in the outpatient clinics and could opt out if they disagreed with their child’s participation. Participation in the study was fully voluntary and anonymous, with no explicit incentives provided for taking part. We obtained data on 68 adolescents aged from 11 to 16 years (response rate 100.0%; mean age: 13.27; 48.5% boys). The study was approved by the Ethics Committee of the Medical Faculty at P. J. Safarik University in Kosice as well as by the Ethics Committee of Children’s Hospital in Bratislava.

Measures
DM-related limitations in active participation were assessed by items derived from the Diabetes Quality of Life for Youth questionnaire (Skinner et al., 2006). Adolescents were asked how often does diabetes (1) limit their social relationships and friendships, (2) interfere with them exercising, (3) interrupt their leisure-time activities, (4) prevent them from doing activities at school. Responses were dichotomized into two categories as follows: (1) rarely and never, (2) sometimes, often and always.

Two subscales of the Diabetes Quality of Life for Youth questionnaire (Skinner et al., 2006) were used to measure adolescent-reported personal and parental worries (7 and 3 items, respectively). Each item has five possible scores from 0 to 4, with 0 representing ‘never’ and 4 ‘all the time’. Sum scores were transformed into a 0-100 scale. Higher scores indicate a more negative impact of diabetes and poorer quality of life, and lower scores indicate better quality of life. Cronbach’s alpha values indicated the good internal consistency of both subscales (parental worries = .72, personal worries = .89).

Statistical analyses
First, we described the sample using descriptive statistics. Next, we examined the associations of adolescent-reported personal and parental worries with DM-related limitations in social relationships, exercising, activities at school and leisure-time activities using a logistic regression model adjusted for gender. All analyses were performed using SPSS version 21.0.

Results
The sample and variables are described in Table 1. A considerable proportion of adolescents reported DM-related limitations in their activities. More than 25% of them reported limitations in social relationships, 35% in exercising, 39% in leisure-time activities and 37% in school-related activities.
The results of the logistic regression analyses show that adolescents who reported parental worries had a significantly higher chance per worry of reporting limitations in social relationships (Odd ratio (OR) = 1.034, 95% confidence interval (CI) 1.000-1.070), leisure-time activities (OR/95%CI: 1.029/1.001-1.058) and school activities (OR/95%CI: 1.035/1.004-1.067). In contrast, perceived personal worries were significantly associated with reporting limitations in social relationships (OR/95%CI: 1.042/1.004-1.082) and in exercising (OR/95%CI: 1.055/1.018-1.094) (Figure 1).

Discussion

Our objective was to explore the parent- and personally perceived barriers to active participation among adolescents with DM-1. We found that adolescents who reported more parental worries have a higher chance of reporting limitations in social relationships, leisure-time activities and school activities. Personal worries of adolescents were associated only with limitations in exercising and in social relationships. All the associations were relatively weak.

Our finding of an association between perceived parental worries and limitations in active participation is supported by other studies, indicating a negative association of DM and parent-child functioning (Carroll & Marrero, 2006). Parents and children together are responsible for integral parts of disease management, such as daily blood-glucose monitoring and insulin injections, regular exercise and eating habits and compliance with necessary measures in school or other during leisure activities (Missotten et al., 2013). However, parents are very often concerned about self-management, especially when they are losing responsibility for it during adolescence. This is often leads to stressful interactions between themselves and their children (Carroll & Marrero, 2006). This might then lead to parents being overprotective, which could limit their...
child’s independence (Heah et al., 2007) and subsequently decrease their participation (Majnemer et al., 2008). Despite this, parental worries seem to be influential across the whole variety of the child’s daily activities; they could hardly explain the relatively high proportion of children, ranging from 26% to 39%, reporting limitations.

Moreover, we found that personal worries were associated with limitations in social relationship and exercising. Adolescents with diabetes mellitus are more likely to face problems with social competencies due to various limitations related to their treatment and changes of lifestyle (Michaud et al., 2007). Fear of stigmatization and of loss of autonomy appeared to be important barriers to getting required support from their peers, which is associated with a decrease of regimen adherence (Dalamater et al., 2014). Personal factors, including fear and lack of skills (physical and social), were also identified as barriers to physical activity among children with a health condition (Shields et al., 2012). According to Liese’s (2013) review study, parents’ fear of hypoglycaemia is a particularly highly prevalent barrier to the involvement of their children in physical activities and is very often connected with engagement of parents in hypoglycaemic avoidance behaviour.

Strengths and limitations
This study has strengths as well as limitations. The most important strength is that we reached a high response rate in a chronically diseased adolescent population which is not frequent in Slovakia. According to the National Health Information Centre (2015), in 2015 only 676 children aged from 10 to 14 were being treated for DM in Slovakia. The relatively small sample size is the main limitation, decreasing its power to show associations. Moreover, only adolescent-reported data have been used, representing an adolescent perspective, and we are lacking the perspective of parents. The latter may be important further for understanding barriers to active participation of adolescents with a chronic condition.

Implications
We found that adolescents with DM perceive personal and parental worries which are associated with limitations in active participation. These perceived barriers to active participation should be further assessed, as should facilitators, because they are crucial for designing intervention programs to promote and enhance participation in this group of children. Moreover, the support of parents of children with diabetes should be improved to reduce their worries and in this way also improve the opportunities for active participation of their children.

Conclusion
Adolescents with DM perceive their condition and treatment to have a major influence on their life and participation in daily activities. Personal but especially parental worries seem to be associated with perceived limitations in particular activities, including social relationships, school activities and exercising. Thus, attention should be focused on supporting adolescents with DM in better disease management to prevent these negative side effects of their DM and improve their opportunities for active participation.