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Self-esteem in adolescents with chronic physical illness vs. controls in Northern Russia

Abstract

Objective: This work aims to study self-esteem in adolescents with diabetes, asthma and epilepsy; compare the results with those of the representative sample of healthy adolescents; and evaluate the predictive value of certain demographic, family-related, and disease-related factors on self-esteem.

Methods: A total of 148 chronically ill adolescents and 301 matched healthy counterparts completed the Rosenberg Self Esteem Scale and the “I think I am” questionnaire. Adolescents’ parents answered socio-economic status questions. Disease severity was evaluated by doctors of the outpatient clinic.

Results: Comparison analysis of the three disease groups revealed highest self-esteem perception in adolescents with diabetes, and lowest in adolescents with epilepsy. Unexpectedly, adolescents with diabetes scored higher than their healthy counterparts. There were no significant differences between the reports of adolescents with asthma and controls. In the epilepsy group, self-esteem was predicted mostly by disease severity and socio-economic status in diabetes and asthma groups, as well as by age and gender.

Conclusion: The maintenance of positive self-esteem in adolescents with diabetes and asthma is a very reassuring finding. The other results of our study provide support for recognizing adolescents with epilepsy as a vulnerable group in the society. A multidisciplinary professional approach targeted on adolescents with epilepsy is needed, with focus on factors connected with maturation and gender issues.

Keywords: adolescents; chronic physical illness; self-esteem.

Introduction

Adolescents with chronic physical illnesses (CPI) are currently receiving major attention in the field of pediatric care. Clinicians and other medical professionals working with children with long-term conditions are recommended to pay careful attention to the emotional well-being and social adaptation of these patients. Both parameters have a reciprocal relationship with self-esteem.

The definition of “self-esteem” has changed over time. More than a century ago, William James defined self-esteem as a consequence of competence. Later, Morris Rosenberg introduced self-esteem as a positive or negative attitude toward the self. Finally, Nathaniel Branden defined self-esteem as the belief that one is competent to live and worthy of living (1).

Two important personality dimensions – emotional and cognitive – are reflected in self-esteem and self-concept, respectively. Given that diagnostic assessments (self-report) of these personality dimensions always cover both aspects, it may be justified to perceive self-esteem and self-concept as just one construct, reflecting the way the person evaluates, perceives, and describes his own acceptance and competence (2).

Research by Robins et al. on self-esteem development over age showed a comprehensive picture. Overall, self-esteem was reported in its highest level during childhood, and it declined sharply from ages 9 to 12 years to adolescence (13–17 years) (3). Therefore, adolescence is a crucial stage in maintenance of self-esteem. The decline in adolescents’ self-esteem might be linked to physical, emotional, cognitive, and sociocontextual changes. There are multiple determinants in the developmental trends observed during childhood and adolescence (3). In particular, social perception is attributed to the undoubtedly sensitive structure of adolescent self-esteem (4). Peer relationships and family environment constitute the main source for the decline or rise in self-esteem throughout adolescence.

The study of Torres and Fernandez, which used an adolescent population, found self-esteem to be important for behavioral maintenance of mental health (i.e., avoidance of sadness, control of one’s feelings, maintenance
of self-confidence) and the social aspect of health (i.e., having friend, family, and teachers that care for one, being respectful of others) (5).

Several studies have reported gender disparity in adolescents’ self-esteem. A gender gap emerges when girls and boys reach adolescence, showing higher self-esteem in boys than in girls (3, 4). In the study of Wennström, the link between gender and aspects of negative self-concept was found among children with CPI and their healthy siblings. Girls are less stable in psychological well-being, felt less appreciated, and experienced the lack of security in their family relations (6).

The maintenance of positive self-esteem is more complicated if a child experiences a chronic condition (7). The latter is contradicted by studies reporting self-concept of CPI similar to that of healthy children (8). Several comparative studies between children with diabetes and controls reported encouraging results. Greek children with diabetes exhibited high self-esteem, similar to that of the healthy control group (9). Furthermore, in a Turkish study, children with diabetes reported higher self-esteem scores than the control group (10). Nevertheless, different disorders might have a diverse influence on the self-concept of the child. The comparative study on children with epilepsy and asthma showed significantly lower self-concept levels in the epilepsy group (11).

Few studies focused on self-esteem difficulties experienced by CPI adolescents in Northern Russia. Therefore, the present study was undertaken to investigate the outcomes regarding self-esteem in three adolescent disease groups, namely, diabetes, asthma, and epilepsy. The aims of the present study were as follows: (a) to study self-esteem in adolescents with diabetes, asthma and epilepsy; (b) to examine the predictive value of certain demographic, family-related and disease-related factors on self-esteem; and (c) to compare self-esteem in chronically ill adolescents with a representative sample of children in the general community.

Materials and methods

Subjects and the procedures

A total of 173 potential participants were identified from the records of child outpatient clinics in Arkhangelsk (Northern Russia) in December 2002. The inclusion criteria were age from 13 to 16 years old and must be diagnosed at least 1 year prior the data collection with one of the following physical chronic conditions: diabetes, asthma, and epilepsy. Exclusion criteria were mental retardation, living in an institution, or having more than one chronic condition. All adolescents with diabetes who were visiting Arkhangelsk child outpatient clinic at the start of the data collection (autumn 2002) and who met our inclusion criteria were invited to participate in our study. Altogether, 55 adolescents with diabetes mellitus matched our inclusion criteria. For the purpose of the investigation, approximately the same number of adolescents with asthma and epilepsy were chosen. Studying the outpatient clinics registers from the three largest districts of Arkhangelsk, we selected for recruitment every second adolescent with epilepsy (n=59) and every third with asthma (n=59) matching our criteria. About 91% of mother/CPI adolescent dyads agreed to participate in the study; however, the refusal rate was higher in the epilepsy group (15%). Adolescents who were inpatients during the period of data collection (n=5) were excluded from the study sample. Three families (two with adolescents with epilepsy and one with asthma) were out of reach. Thus, the final sample consisted of 168 adolescents [diabetes (n=50), asthma (n=50), and epilepsy (n=68)]. The socio-demographic and disease-related characteristics of the study sample can be found in Table 1.

Comparative data were obtained from a group of 301 schoolchildren and their mothers from secondary schools in each of three largest administrative districts of the city. Adolescents were chosen on the basis of age to match our subjects. Any child with documented chronic illness, as noted in the school medical records, was excluded from the study. There were no drop outs in the control group.

The test sheets were individually completed by adolescents (CPI group at the outpatient clinic or at home; control group in school) and their mothers (CPI group at the outpatient clinic or at home; control group at home) in a paper-pencil test format. In the CPI study group setting, the investigator observed the filling of the questionnaires to minimize the bias of parent/child presence.

Instruments

Rosenberg Self Esteem Scale (RSES)

RSES (12) is a 10-item Guttman scale of self-esteem. Respondents are asked to strongly agree, agree, disagree, or strongly disagree with each of the items. “Positive” and “negative” items are alternated in an attempt to reduce the effect of respondent bias. At least six items must be scored as positive for a respondent to be considered to have low self-esteem. This instrument is one of the most widely used for evaluating the global feeling of self-worth. It has been validated extensively for high school students and is the most accepted self-esteem scale in this population (4). RSES was used earlier in the research of adolescents with CPI (13). This questionnaire was translated into Russian language, and used on a special subgroup of male adolescents versus controls by Ruchkin et al. (14).

I think I am

The test (15) is the measure of self-evaluation consisting of 72 statements scored from −2 to +2. The instrument can be used in children aged 10 to 18 years. The complete scale can be divided into five sub-scales, namely, “Physical characteristics”, “Skills/talents”, “Psychological well-being”, “Relationship to the family”, and “Relation to others”. Age and gender are taken into consideration before the final
score is expressed in the standardized 9-point stanine scale, in which higher scores indicate higher self-esteem. This instrument has been standardized on a sample of Swedish children and is commonly used in medical research studying self-esteem of children with different CPI (6). The translation of “I think I am” self-evaluation questionnaire into Russian followed established guidelines (16), including the appropriate use of independent back translation by official interpreter.

Clinical data

Clinical data was withdrawn from the medical files of the patients at the outpatient clinics. These included type of the disease, age at clinical diagnosis, and disease duration. Disease severity was evaluated by CPI adolescents’ physicians.

Two questions (1st to evaluate the level of the disease control and 2nd to evaluate the patient’s present condition) with four alternative answers each were asked in paper-pencil format: “very bad” = 1, “bad” = 2, “good” = 3, and “very good” = 4. The following determinants were taken into consideration by physicians: epilepsy-type of seizure, seizure frequency, antiepileptic medications, observed side effects, number of hospitalizations; asthma – frequency of asthmatic episodes, medication side effects, number of hospitalizations; and for diabetes – level of metabolic control, number of hypoglycaemic episodes, disease complications, and number of hospitalizations.

Socio-economic status

Given that no available SES classification scheme for Russia was found, the education, occupation level, and the level of income of the mothers or fathers were obtained. The scores for the education levels were as follows: 0 = high school level, 1 = college education and incomplete university education, and 2 = 5 or more years of university. The scores for the occupation level were as follows: 0 = unskilled and manual workers, 1 = blue collar or technical workers, and 2 = white-collar workers. For the income level, there were three alternative answers, namely, 0 = low, 1 = average, and 2 = high income.

Certain recoding manipulations were executed in order to analyze the associations between aspects of self-esteem and socio-economic variables. In two parent families, the highest rating for parent occupation and education was used. The categories were then summed into following classes: 2 = high SES of the family (range, 5–6); 1 = average SES (3–4); and 0 = low SES (0–2).

Ethics

There was no ethical research committee in Arkhangelsk at the time of the project planning and data collection. Thus, informed consent from the head of child outpatient clinics and school principals was obtained. Informed consent was also obtained from all the participants (both mothers and adolescents), and they were also informed about the voluntary and confidential nature of their participation in the study. They were assured that the staff of the outpatient clinics would not receive any private information from the questionnaires beforehand.

Data analysis

All variables were presented as means with standard deviation, and Cronbach’s α was used to determine the internal consistency reliability of the questionnaires. CPI and control groups were compared by Student’s t-test and Mann-Whitney test. General linear model (GLM) was used to investigate the predictive value of certain demographic (adolescent age, gender, SES), family (family size, single-parent household, parental separation/death), and disease-related (disease severity, disease duration and age of onset, as well as HbA₁c level).
in the diabetes group) factors on adolescents self-esteem. The contribution of each factor (the effect size) was estimated by partial $\eta^2$ measure. RSES score and the total “I think I am” score were analyzed as dependent variables. For all analyses, a two-tailed $p<0.05$ denoted statistical significance.

### Results

Internal consistency, assessed by Cronbach’s $\alpha$ coefficient, was found to be satisfactory ($\geq 0.70$) in the RSES and in four of the “I think I am” subscales (Skills/talents, Psychological well-being, Relationship to the family, and Total). Two subscales, Physical characteristics and Relations to others, were excluded from the analysis due to low internal consistency (Table 2).

Generally our RSES results in the CPI and Control group populations are comparable with Ruchkin’s control group of 103 adolescents from the same region, although our results are different from the low level of self-esteem found in the delinquent subjects in that study (14).

There were significant differences found within the CPI groups. Adolescents with diabetes scored higher on Relations to family ($p<0.01$) and Total subscale ($p<0.05$) than their peers with asthma. They also scored higher on Skills ($p<0.001$), Relations to family ($p<0.001$), Total subscale ($p<0.001$), and RSES ($p<0.01$) than their peers with epilepsy. Adolescents with asthma scored higher on Skills ($p<0.001$), Total subscale ($p<0.05$), and RSES ($p<0.05$) than those with epilepsy.

General linear model for self-esteem predictors using results of both the “I think I am” questionnaire and RSES was performed (Table 3). The independent variable disease severity was the most constant statistically significant predictor for self-esteem perception in the diabetes group. Among the variables, disease severity, SES, and family size, appeared to be significant predictors for self-esteem in adolescents with asthma, with the latter having a rather modest effect size. Meanwhile, adolescents’ age accounted from 14% to 19%, and gender accounted for only 9% of the variation in the reports in epilepsy group. All regression coefficient signs were in the expected direction. Less disease severity, higher SES, and bigger family size were related to higher self-esteem. Older age predicted high self-esteem in adolescents with epilepsy, and vice versa in the diabetic group. None of the variables used in the model for CPI adolescents had a predictive value in the Control group.

Next, comparative analysis of the whole CPI group vs. Controls showed significant differences between the self-esteem reports. Unexpectedly, adolescents with CPI scored higher on Psychological well-being ($p<0.05$) and RSES ($p<0.05$).

Finally, each disease group comparison with controls was performed. Adolescents with diabetes scored higher on Psychological well-being ($p<0.05$), Relations to family ($p<0.001$), Total subscale ($p<0.01$) and RSES ($p<0.01$) than controls, while adolescents with epilepsy scored lower on Skills ($p<0.001$), Relations to family ($p<0.01$), and Total subscale ($p<0.01$) than the Control group. No differences were found between adolescents with asthma and controls.

### Discussion

The maintenance of positive self-esteem is believed to be important for ensuring psychological well-being, adjustment, and effective management of the chronic illness (17, 18). In our study, adolescents with different CPI showed diverse levels of self-esteem. Adolescents with diabetes scored higher on all but one aspects of self-concept compared with their peers with epilepsy, and higher on a general level compared to adolescents with asthma. This was not an unexpected finding considering the outcomes of our previous study, wherein

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### Table 2: Cronbach’s $\alpha$ coefficients, mean values, and standard deviations of the “I think I am” subscales and the RSES.

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Mean±SD</th>
<th>Asthma Mean±SD</th>
<th>Epilepsy Mean±SD</th>
<th>Controls Mean±SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think I am</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>0.62</td>
<td>14.72±8.23</td>
<td>12.68±6.7</td>
<td>10.52±8.56</td>
</tr>
<tr>
<td>Skills</td>
<td>0.72</td>
<td>9.26±9.67</td>
<td>9.22±8.86</td>
<td>3.42±5.40</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>0.73</td>
<td>13.06±9.22</td>
<td>12.56±6.77</td>
<td>10.77±6.86</td>
</tr>
<tr>
<td>Relation to family</td>
<td>0.81</td>
<td>18.26±7.29</td>
<td>12.35±11.55</td>
<td>9.56±9.11</td>
</tr>
<tr>
<td>Relation to others</td>
<td>0.61</td>
<td>13.74±7.91</td>
<td>9.32±6.17</td>
<td>8.33±3.59</td>
</tr>
<tr>
<td>Total</td>
<td>0.89</td>
<td>69.04±33.29</td>
<td>56.13±26.46</td>
<td>42.6±23.0</td>
</tr>
<tr>
<td>RSES</td>
<td>0.76</td>
<td>32.04±4.31</td>
<td>31.36±4.16</td>
<td>29.71±2.95</td>
</tr>
</tbody>
</table>
adolescents with diabetes showed fairly good mental health states and not being at risk for developing behavioral problems compared with their peers with asthma and epilepsy (19).

Our data analysis suggests that self-esteem in adolescents with diabetes is primarily determined by the disease severity status. A number of studies have shown that youths perceive diabetes as upsetting and difficult to manage (20). Such perceptions may be due to the difficulties of maintaining metabolic control partly owing to the decrease of insulin sensitivity associated with puberty (21). The latter often leads to the increase in frequency of hypoglycemic episodes and hospitalization. The results of our GLM analysis support previous research indicating higher self-esteem scores in younger than in older youths (18), which is psychologically and clinically relevant. The older adolescents may perceive diabetes as a restraining and restricting life factor, a threat to future health status, and a limitation of their life choices. At the same time, parents of the older adolescents tend to provide less disease-specific support and are usually less involved in the diabetes care (22), leaving all the disease burden on the adolescent. This is a controversial finding because adolescents might develop better coping mechanisms and a tendency to more adaptive response to the diabetes as they mature (23).

Meanwhile, the self-esteem scores in the asthma group were relatively high. An earlier study reported that a midadolescence asthma sample scored close to population norms and was not at risk for behavioral problems (24). Our analyses suggested that self-esteem in this study group was not only related to disease and its implications but also to the socioeconomic context in which it was set. Asthma severity and socioeconomic status were proven to predict emotional reactions to asthma in pediatric patients (25). Family size was a slightly less important factor influencing self-esteem, but defiantly worth mentioning in the scope of this paper. This finding gives important evidential support for the DeBois and Hirsch self-esteem model (26), where family is viewed as being part of the primary context influences on adolescents’ self-esteem.

Comparison analysis of three disease groups revealed that adolescents with epilepsy reported lowest self esteem. The reasoning behind this outcome can be drawn from different dimensions of adolescent life, such as the CNS involving disease, the lack of social support, and stigmatization associated with the illness. Although disease severity is an obvious contributor to self-esteem perception in CPI adolescents, we did not find its influence on the epilepsy group. The strongest predictive
relationship was determined between self-esteem and older age of adolescents with epilepsy. Maturation appeared to be associated with the adjustment to chronic condition, better regime compliance, and successful condition control resulting in positive self-perception. A solidified sense of self, older age as a personal resource with more life experiences, and more confidence are the explanations given by Austin et al. (27). Despite being relatively small, the group showed diverse results with respect to the demographic factors of age and gender. Girls with epilepsy reported more positive self-esteem than boys, although it was significantly higher but with a much smaller effect size. This corresponds with our previous findings wherein boys with epilepsy experienced more psychological disturbances than girls (19). Stigma is closely connected to gender and illness management. Stigma affects the person though socio-psychological processes that involve the person’s perception of oneself; low self-esteem is just one outcome of stigmatization (28). For boys who are trying to keep CPI out of their personal and social identities, illness might be an isolating and threatening experience in a society where they are expected to be physically fit and tough (29).

The complexity of the variables related to the perception of self-esteem was first presented by DeBois and Hirsch in a general conceptual model of self-esteem in early adolescence (26). A multidimensional structure of self-esteem in their model is influenced by a complex of individual (physical, cognitive, behavioral developmental status) and contextual (such as peers, family, and school) factors, with bidirectional linkage to adjustment outcome. In our work, we suggested that chronic physical illness might interfere in both background factors changing self-perception of the adolescent in a negative direction. This hypothesis proved to be wrong at least for two study groups. Adolescents with diabetes reported higher self-esteem than their peers from the control group, and there were no significant differences between the reports of adolescents in the asthma and control groups. The manifestation of these two chronic physical illnesses during childhood has received major attention from all kinds of clinical professionals. Such professionals are the ones who help youths go through the long period of awareness of disease after diagnosis; convince adolescents on compliance with follow-up visits and proper disease management; and give education and knowledge on the disease itself and its course. All this may enable youths to avoid hypersensitivity, instability, self-consciousness and lack of self-confidence, which are the chief characteristics of low self-esteem identified in a previous work (30). Adolescents with epilepsy, in contrast, receive less support and attention from the society. Taking into consideration the stigmatizing effect of the disease involving CNS as well as the prevailing prejudice and social conventions, we can identify the epilepsy group as the most vulnerable one.

Clearly, the important goal of CPI management, aside from the achievement and maintenance of adequate disease severity status, is to insure that adolescents develop optimally in all aspects of life – psychologically, socially and physically. Positive self-esteem and self-concept are the bases of their successful functioning. Therefore, we suggest a routine application of measures to assess CPI adolescents’ development status and current psychological condition in clinical practice.

Limitations

Caution must be exercised in interpreting the analysis between two severity groups owing to the small sample size in this study. The chosen method of disease severity evaluation might also be controversial. The CPI severity evaluation conducted by doctors in charge of the cases was chosen to describe the overall severity of the conditions and to simplify the assessment of the relationship between the CPI and fundamental psychological as well as socio-demographic factors.

Conclusion

The first and very reassuring finding of our study showed that adolescents with diabetes and asthma maintained positive self-esteem similar to or even higher than that of their healthy counterparts. The second important finding involved the identified vulnerable group of adolescents with epilepsy, which was found to be at an elevated risk for impaired self-esteem. The third contribution involved the diversity of factors contributing to the self-esteem variations in the three CPI groups. Disease severity and SES were associated with self-esteem in the diabetes and asthma groups, while age and gender related to self-esteem in adolescents with epilepsy.

Gaining a better understanding of the process of formation and maintenance of self-esteem in children with epilepsy, especially during the period of transition from childhood to adolescence, is greatly needed. We found that aside from disease control and patients’ present
condition, factors connected with the maturation and gender issues must be considered as well. A multidisciplinary approach involving pediatricians, school nurses, psychologists, and teachers might contribute to more positive self perception of adolescents with epilepsy.

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