A national survey of the psychological well-being of adolescents with diabetes and their parents: first results from Diabetes MILES Youth – Australia

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Background

- Managing type 1 diabetes is challenging at any age, particularly during adolescence, and places substantial behavioural and psychological burden on young people and their families.
- The Diabetes MILES Youth Study (MYS) is the first large-scale Australian survey on the psychosocial aspects of living with diabetes among adolescents (10-19 years) with type 1 or type 2 diabetes (T1D / T2D) and their parents.

Aim

- To examine psychological well-being among young people with type 1 diabetes and their parents.

Method

Recruitment

- By invitation posted to 6,345 (59%) National Diabetes Services Scheme (NDSS) registrants aged 10-19 years (n=5,508 with T1D) and their parents, who had consented to being contacted for research. Advertised via flyers, publications and social media.
- The online survey was open for 8 weeks (August-October 2014).

Survey content

- Demographic characteristics (age, gender, socio-economic status (SES), family situation, location).
- Clinical data (self-report HbA1c, diabetes duration, treatment).
- WHO-5 Index to assess general emotional well-being. Total score (range 0-100); <50 impaired well-being.
- PHQ-8 to assess depressive symptoms – only youth 13-19 years – over the past two weeks; rated 0 (not at all) to 5 (nearly every day). Higher total scores indicate more severe depressive symptoms; minimal (0-4), mild (5-9), moderate (10-14), moderately-severe (15-19) and severe (20-24).
- Adolescents perception of having ‘too much responsibility for diabetes care’, a single item from the MIND Youths Questionnaire, rated 0 (never) to 5 (all the time).

Data analysis

- Data were analysed using SPSS (Version 22.0, NY): differences in age, socio-economic status, country of birth, type 1 diabetes and their parents.

Survey

Table: Sample characteristics

<table>
<thead>
<tr>
<th>N (%)</th>
<th>Mean ± SD (Range)</th>
<th>Youth</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender - female</td>
<td>474 (61)</td>
<td>727 (88)</td>
<td></td>
</tr>
<tr>
<td>Age - years</td>
<td>14±3</td>
<td>46±6</td>
<td></td>
</tr>
<tr>
<td>10-12</td>
<td>230 (29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13-15</td>
<td>277 (35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-17</td>
<td>153 (20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-19</td>
<td>121 (15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander background</td>
<td>14 (2)</td>
<td>9 (1)</td>
<td></td>
</tr>
<tr>
<td>Country of birth - Australia</td>
<td>714 (91)</td>
<td>659 (80)</td>
<td></td>
</tr>
<tr>
<td>Socio-economic status - IRSAD</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
</tr>
<tr>
<td>130 (17)</td>
<td>284 (38)</td>
<td>340 (45)</td>
<td></td>
</tr>
<tr>
<td>121 (15)</td>
<td>320 (39)</td>
<td>372 (46)</td>
<td></td>
</tr>
<tr>
<td>Geographical location (RAS)</td>
<td>Major cities</td>
<td>Regional / Rural</td>
<td></td>
</tr>
<tr>
<td>517 (68)</td>
<td>256 (33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>548 (67)</td>
<td>238 (32)</td>
<td>265 (33)</td>
<td></td>
</tr>
<tr>
<td>Diabetes duration - years</td>
<td>6±4 (0-18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment regimen</td>
<td>Insulin pump</td>
<td>2 injections/day</td>
<td>≤ 2 injections/day</td>
</tr>
<tr>
<td>408 (52)</td>
<td>294 (39)</td>
<td>61 (8)</td>
<td></td>
</tr>
<tr>
<td>Self reported HbA1c - mmol/mol (%)</td>
<td>64±7 (8.0±1.6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Data analysis

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Results

Sample characteristics

- People from regional/rural Australia were well represented. Girls and pump users were over-represented (see Table 1).
- Mean self-reported HbA1c was slightly lower than the average clinic population.

Youth emotional well-being

- 28% (n=217) reported impaired emotional well-being (score <50).
- Those aged 16 - 19 years had the highest rate of impaired well-being; the youngest age group (10-12 years) (41% vs 19%, p<0.001 (Figure 1).
- Girls scored <50 more frequently than boys (34% vs 19%, p<0.001) as did youth from single-parent vs 2-parent families (38% vs 26%, p<0.05), and those using insulin injections vs pump (32% vs 24%, p<0.05).
- Impaired well-being was associated with higher HbA1c (r=0.23, p<0.001) and ‘too much responsibility for diabetes care’ (n=0.23, p<0.001) and ‘too much responsibility for diabetes care’ (n=0.23, p<0.001).

Youth depressive symptoms

- 25% (n=138) of youth aged 13-19 years reported moderate to severe depressive symptoms (PHQ-8 score ≥10) (see Figure 2).
- Seventy of symptoms was greater with older age; 18% of those aged 13-15 years scored ≥10 compared with 32% aged 16-19 years, p<0.001.
- Moderate-to-severe symptoms were more likely to be reported by girls vs boys (31% vs 16%, p<0.001) and youth using insulin injections vs pump (29% vs 21%, p<0.05).
- Depressive symptoms were associated with higher HbA1c (r=0.24, p<0.05) and ‘too much responsibility for diabetes care’ (n=0.34, p<0.001), but not with family situation, SES or diabetes duration.

Responsibility for diabetes care

- 18% (n=141) of young people perceived they ‘often’ or ‘always’ had too much responsibility for their diabetes care; girls more so than boys (23% vs 12%, p<0.001), as did youth from single-parent vs two-parent families (23% vs 17%, p<0.05).
- Too much responsibility was weakly correlated with higher HbA1c (r=0.20, p<0.001), but not with age, HbA1c, insulin pump use or diabetes duration.

Parents’ emotional well-being

- 34% (n=279) reported impaired well-being (score <50).

Conclusions

- Around one in four young people with T1D reported impaired emotional well-being or moderate to severe depressive symptoms, higher than reported in similar cohorts.
- Older adolescents, girls and those using injections to manage diabetes reported poorer psychological well-being. Impaired well-being and depressive symptoms were associated with sub-optimal HbA1c and the perception of having too much responsibility for diabetes care.
- Considering the MYS respondents’ SES and clinical advantages, the impact of diabetes on psychological well-being is likely to be under-estimated the burden for young Australians with T1D and their parents.
- In-depth analyses are ongoing and study results will continue to highlight the unmet psychological needs of young people with T1D and their parents and how policy and practice can be improved.

References


Enquiries:

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NDSS Infoline 1300 136 588 ndss.com.au