

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=5,928 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 Index¹ to assess general emotional well-being. Total score (range 0-100); <50 impaired well-being.
- PHQA-8² to assess depressive symptoms (only youth 13-19 years) over the past two weeks; rated 0 (not at all) to 3 (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 Youth Questionnaire³, rated 0 (never) to 5 (all the time).

Data analysis

- Data were analysed using SPSS (Version 22.0, NY): differences between groups (Chi-square tests), relationships among variables (Spearman rank correlations).

Table 1: Sample characteristics

N (%) or Mean ± SD (Range)	Youth	Parents
Gender - female	474 (61)	727 (88)
Age - years	14±3	46±6
Age group - years		
10-12	230 (29)	
13-15	277 (35)	
16-17	153 (20)	
18-19	121 (15)	
Aboriginal or Torres Strait Islander background	14 (2)	9 (1)
Country of birth - Australia	714 (91)	659 (80)
Family situation		
Two parent family	674 (86)	708 (86)
Single parent family	85 (11)	117 (14)
Socio-economic status - IRSAD		
Low	130 (17)	121 (15)
Medium	284 (38)	320 (39)
High	340 (45)	372 (46)
Geographical location (RAS)		
Major cities	517 (68)	548 (67)
Regional / Rural	238 (31)	265 (33)
Diabetes duration - years	6±4 (0-18)	
Treatment regimen		
Insulin pump	408 (52)	
≥ 3 injections/day	294 (39)	
≤ 2 injections/day	61 (8)	
Self reported HbA1c - mmol/mol (%)	64±7 (8.0±1.6%)	

IRSAD: Index Relative Socioeconomic Advantage and Disadvantage
RAS: Remoteness Area Structure

Figure 1: Youth emotional well-being by age group

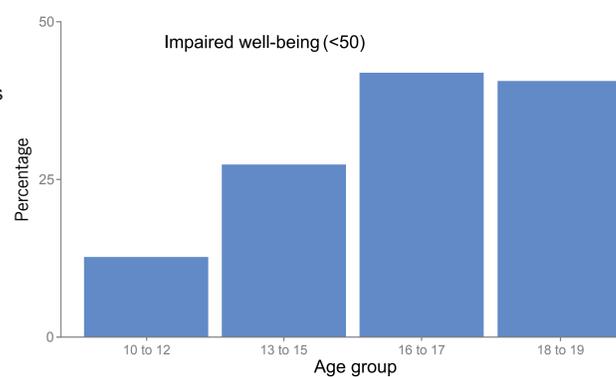
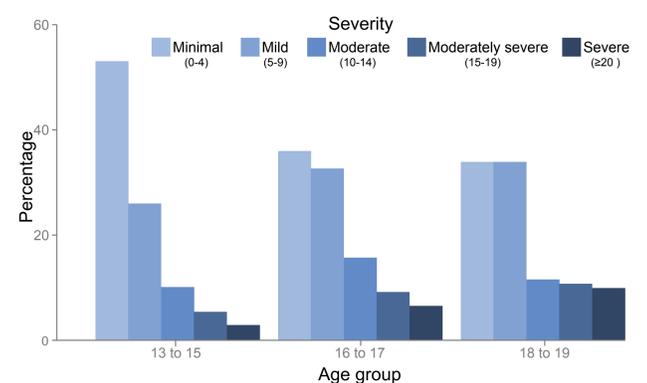


Figure 2: Youth depressive symptom severity by age group



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 population⁴.

Youth emotional well-being

- 28% (n=217) reported impaired emotional well-being (score <50).
- Those aged 16 - 19 years had 3 times the rate of impaired well-being than the youngest age group (10-12 years) (41% vs 13%, 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' (r=-0.28, p<0.001). There was no association with SES or diabetes duration.

Youth depressive symptoms

- 25% (n=138) of youth aged 13-19 years reported moderate to severe depressive symptoms (PHQA-8 score ≥10) (see Figure 2).
- Severity 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<0.001) and 'too much responsibility for diabetes care' (r=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 (29% vs 17%, p<0.05).
- Too much responsibility was weakly correlated with higher HbA1c (r=0.20, p<0.001), but not with age, SES, 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 cohorts⁵.
- 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 under-estimate 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

- De Wit M, et al. (2007). Validation of the WHO-5 Well-Being Index in adolescents with type 1 diabetes. *Diabetes Care*, 30(8), 2003-2006.
- Johnson J, et al. (2002). The patient health questionnaire for adolescents: validation of an instrument for the assessment of mental disorders among adolescent primary care patients. *Journal of Adolescent Health*, 30(3), 196-204.
- de Wit M, et al. (2012) Assessing diabetes-related quality of life of youth with type 1 diabetes in routine clinical care: the MIND Youth Questionnaire (MY-Q). *Pediatric Diabetes*. 13(8): p. 638-646.
- Cameron F, et al. (2013). Short report: Care for children and adolescents with diabetes in Australia and New Zealand: Have we achieved the defined goals? *Journal of Paediatrics And Child Health*, 49(4), E258-E262.
- Lawrence J et al. Prevalence and Correlates of Depressed Mood among Youth With Diabetes: The SEARCH for Diabetes in Youth Study. *Pediatrics*, 2006. 117(4): p. 1348-1358.

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