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Highlighting the unmet needs of Australian adults with diabetes:
First results from Diabetes MILES – Australia

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In July 2011, The Australian Centre for Behavioural Research in Diabetes undertook a national survey of adults with type 1 and type 2 diabetes. The survey focused on the psychological, social, and behavioural aspects of living with diabetes.

This study, known as Diabetes MILES (Management and Impact for Long-term Empowerment and Success) – Australia, was the largest ever national survey to examine these issues. Over 3,300 Australian adults with diabetes took part in this landmark study. Details of how the study was conducted have been published elsewhere.¹

Initial findings reveal what it is like to live with diabetes, and highlight some of the unmet needs of Australian adults with diabetes in the following key areas: (1) emotional well-being, (2) self-management, (3) healthcare and (4) social support.

Emotional well-being

Diabetes-related distress refers to the impairment of emotional well-being caused by or related to living with and managing diabetes. The severity of such distress can vary from time to time and from person to person. Most people with diabetes experience some level of diabetes-related distress at some point in their lives.

In the Diabetes MILES – Australia study, diabetes-related distress was measured using the Problem Areas In Diabetes (PAID) scale. Among those who participated in Diabetes MILES - Australia:

- One in five had severe diabetes-related distress (as indicated by a score of ≥40 on the PAID scale).
- Diabetes-related distress was higher amongst younger adults.
- After adjusting for age, gender, and duration of diabetes, the distress levels of participants with type 1 diabetes and insulin-treated type 2 diabetes were statistically equivalent, and the latter group has significantly higher distress than those with non-insulin-treated type 2 diabetes.

The Diabetes MILES - Australia survey also included measures of depressive symptoms (9-item Patient Health Questionnaire, or PHQ-9) and anxiety symptoms (7-item Generalised Anxiety Disorder scale, or GAD-7). The results indicated:

- One in four participants had moderate-to-severe symptoms of depression.
- Around one in six had moderate-to-severe symptoms of anxiety.
- As with diabetes-related distress, younger age was associated with more symptoms of both depression and anxiety.
- People with insulin-treated type 2 diabetes reported more depressive symptoms than people with type 1 diabetes and people with non-insulin-treated type 2 diabetes (after adjusting for age, gender and diabetes duration).
- Participants with insulin-treated type 2 diabetes had significantly more anxiety symptoms than those with type 1 diabetes, but all other comparisons were non-significant.

Results from Diabetes MILES - Australia indicate that emotional problems are relatively common among adults with type 1 and type 2 diabetes. This is consistent with international studies. The findings also highlight that younger adults and those using insulin (whether they have type 1 or type 2 diabetes) may be groups requiring specific support for coping with emotional problems.

Self-management

When asking people with diabetes to report on their self-management activities, the focus is often solely on the frequency with which they have engaged in particular behaviours (e.g. healthy eating, physical activity). However, this approach does not take into account the individual’s evaluation of the importance of the behaviour, or the impact it has on their lives.

The Diabetes MILES - Australia survey included a new measure of diabetes self-management (Diabetes Self-Care Inventory - Revised, or DSCI-R). The DSCI-R asks not only about the frequency of self-management activities, but also about how important and how burdensome each activity is to the person.

The majority of respondents reported they always took the required number of insulin injections per day (type 1: 81%, type 2 (insulin-treated): 78%). Even higher proportions of participants perceived this to be very important (type 1: 89%, type 2 (insulin-treated): 85%). Insulin injections were perceived to be a great burden by only 7% of people with type 1 diabetes, and just 3% of people with insulin-treated type 2 diabetes.

Most participants reported that they often or always ate a healthy diet (type 1: 56%, type 2: 50%). However, less than half of respondents perceived a healthy diet to be very important.

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Almost half (45%) of all respondents had not been asked what was important to them in their diabetes management by a healthcare professional recently. Furthermore, 51% had not received adequate information from their healthcare professionals. These findings suggest that healthcare professionals may need to work more collaboratively with people with diabetes to ensure their top-priority concerns are addressed in each consultation.

**Social support**

On the whole, Diabetes MILES - Australia participants were highly satisfied with the level of social support available to them. Only 5% of participants indicated that they were not at all satisfied.

Respondents reported high levels of support from their families, and low levels of family conflict in relation to their diabetes. While only 6% were involved in a support group, 32% indicated they were interested in joining a group. This reveals one avenue for future program development for diabetes organisations and community health centres.

**Conclusions and future directions**

The Diabetes MILES - Australia 2011 survey has revealed important findings in relation to the emotional well-being of adults with diabetes, as well as their self-management activities and experience of healthcare and social support. Importantly, the study results highlight the unmet needs of Australian adults with diabetes.

Previous research has often failed to distinguish adequately between type 1 and type 2 diabetes. In contrast, findings from Diabetes MILES - Australia highlight the response profiles of adults with type 1 and type 2 diabetes and those using different treatment regimens. This allows us to build the evidence specifically for each group.

In-depth analyses of the Diabetes MILES - Australia dataset are ongoing. Many posters were presented at the recent ADS–ADEA Annual Scientific Meeting, and journal articles are in active preparation. The results will continue to reveal areas of policy and practice that need to be improved to optimise diabetes care in Australia.

Diabetes MILES is now an international collaborative, co-led by Prof Jane Speight and Prof Frans Pouwer. Diabetes MILES - The Netherlands has also been completed, and plans are underway to conduct studies in other countries.

**Find out more**

- Visit www.acbhrd.org.au and sign up to ‘Research Round-Up’, a free monthly e-newsletter from The Australian Centre for Behavioural Research in Diabetes.

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**References**